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Social capital and community TB care in the Free State, South Africa

Where do TB patients turn for help in the South African health care system? Do they go to a clinic or a community health centre for ambulant treatment, thus retaining contact with their families and local communities? Or are they hospitalised, which means that they can no longer perform their normal duties? In order to answer these questions, a data set was compiled on the basis of oral interviews with a stratified random sample of 310 pulmonary TB patients in the Free State province. A logistic regression analysis of the data revealed that TB patients who can rely on an extended network of relationships, with relatively large amounts of social capital at their disposal, generally make use of clinic treatment and community TB care. Clinics play a central role in TB control programmes, not only as a locus of treatment, but also as a point from which patients can be referred to higher echelons in the healthcare system.

Sociaal kapitaal en lokale zorg voor TB-patiënten in de Vrijstaat, Zuid-Afrika

Waar ergens in het Zuid-Afrikaanse gezondheidszorgsysteem komt een TB-patiënt terecht? Wendt hij zich tot een kliniek of een lokaal gezondheidscentrum voor een ambulante behandeling en behoudt hij zijn contacten met zijn familie en lokale gemeenschap? Of wordt hij gehospitaliseerd, met als gevolg dat hij niet langer kan voldoen aan zijn gewone rolvplichtingen? Om op deze vraag te antwoorden, maken we gebruik van een dataset die werd samengesteld op basis van mondelinge interviews bij een gestratificeerde toevallige steekproef van 310 pulmonaire TB-patiënten uit de Vrijstaat provincie. Uit een logistische regressieanalyse van de gegevens blijkt dat TB-patiënten die op een uitgebreid netwerk van relaties kunnen terugvallen en verhoudingsgewijs over veel sociaal kapitaal beschikken, sterk zijn georiënteerd op een kliniekbehandeling en lokale zorgverlening. In programma's voor tuberculosebestrijding vervullen klinieken een centrale functie, niet alleen als plaats van behandeling maar ook als plaats van waaruit patiënten worden doorverwezen naar de hogere echelons in het gezondheidszorgsysteem.

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Tuberculosis is an illness with many faces. Empirical analysis clearly indicates that TB patients in the Free State province of South Africa are deprived on many levels and that their communal culture of poverty casts a shadow over every aspect of their lives.¹ This was the situation in the country at the beginning of 2000, as in all countries that the World Health Organization had identified as hot spots in the fight against tuberculosis.

Strangely enough, the fact that this phenomenon is so tied up with culture does not mean that it cannot change. The history of the sanatorium movement has taught us that TB can also be interwoven with the cultural values of the elite. From the end of the nineteenth century until the Second World War there were comfortable sanatoria — in South Africa as well as in Western Europe — where the industrial and artistic elite could be treated.

The extremely complex link between TB and the cultural backgrounds of those who become infected, those who become ill, those who are healed and those who die was the motivation for this study. We shall use the concept of social capital to attempt to encompass this complex relationship.

1. Social capital and illness behaviour

The concept of social capital has gained a permanent and very important place in the lexicon of the social sciences in the past decade. It has been theoretically refined and has been applied in very divergent situations, settings and domains. A search on certain bibliographical databases revealed that both “social capital” and “health” appeared as key words. For the period 1999 to 2004 we found 370 publications matching our query in CC Search and Medline.

1 In this study the researchers attempted to highlight the remarkable efforts that are being made in South Africa, and particularly in the Free State, to stem the tide of the TB epidemic. To this end, much deliberation was required in order to supplement the literature and empirical studies. We would like to thank all the individuals and institutions that made such deliberations across the borders of the social sciences and biomedical disciplines possible. We also appreciate the insightful comments of two anonymous reviewers on an earlier version of this paper.

According to Portes (1998), Pierre Bourdieu published the first systematic contemporary analysis of social capital. In some brief notes published in French in 1980, Bourdieu defined social capital as

[...] the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance or recognition (Portes 1998: 3).

Central to Bourdieu's definition are the resources which people garner due to the fact that they are well-connected to others. In addition to this individual-level approach, a macro-level approach has now also appeared in the literature, in which social capital is seen as a collective resource. This latter approach is especially taken in studies on civil society, democratisation, and political development, such as those pioneered by Robert Putnam (Macinko & Starfield 2001: 391).

Recent publications emphasise that social capital is a dynamic concept (Bankston & Zhou 2002: 286-291). The resources constituting it are attained through the various phases of a long acculturation process during which goal-directed social relations are developed, reciprocity and trust cultivated, and common projects set up. Bonding social capital can be important in one phase to reinforce exclusive identities and maintain homogeneity, while bridging capital may totally control another phase, to bring people together across social divides (Putnam 2000: 22-24). Sometimes developing strong ties can be the best way to build up social capital, and at other times weak ties will be better (Field 2003: 66).

Another extremely dynamic concept is that of illness behaviour. Mechanic & Volkart coined this concept in 1961 to describe

[...] the way in which symptoms are perceived, evaluated, and acted upon by a person who recognises some pain, discomfort or other signs of organic malfunction (Young 2004: 1-2).

This concept has withstood the ravages of time very well: it has been theoretically refined, and many hypotheses derived from it have been tested in specific research contexts. As an extension of this theoretical interest, a wide field of applied research has developed in medical sociology, studying illness behaviour as a decision-making process influenced by a series of determinants (Beck *et al* 2002). McKinlay (1972) proposed the following taxonomy for behavioural determinants: economic, socio-demographic, geographical, social-psychological, socio-

cultural and organisational. These have become clichés in the research into illness behaviour and health care utilisation, and have led to a situation in which trying to understand the complex problem of the (circuitous) routes which sick people take in their search for health care has become a multidisciplinary matter. In McKinlay's taxonomy social capital is not yet used as a distinct concept, but research over the last decade has indicated that both social capital and social networks are now common terms (Van Kemenade 2003).

Although the difference between the individual-level and the macro-level approaches is heuristically important, it is difficult to separate these approaches in practice, as they exert a continual mutual influence. Moreover, there are also various types of inter-levels. Social capital is not only located at the individual or the societal level. Between these the informal social group, the formal organization, the community, the ethnic group and even the nation are closely interwoven. Recognising the interaction between the levels creates fascinating research perspectives. Those who wish to transfer control initiatives into the hands of the community soon find that the extent to which supportive community networks are involved is overestimated. Edmondson (2003) warns us not to have unrealistic expectations of such transfers of responsibility, especially not in a neoliberal climate. In their study on the social determinants of TB case rates in the United States, Holtgrave & Crosby (2004: 161) come to the conclusion that "social capital is highly predictive of TB at the state level". Mahendradhata *et al* (2003) argue that TB control, on whatever level it is exercised, and whether it is aimed at case-detection or at treatment, can be successful only if it can rely on strong general health care systems. Studies on social capital are inextricably bound up with multi-level approaches. Within the framework of TB control it is of the utmost importance to take into account the many levels on which social capital finds its origin and at which it resides.

There are also risks attached to the use of the concept of social capital. In the literature it is emphasised that

[...] the concept has been stretched, modified, and extrapolated to cover so many types of relationships at so many levels that the term has lost all heuristic value (Macinko & Starfield 2001: 394).

Indeed, no-one wants one “catch-all” concept. Fassin (2003: 412) warns of the very real danger of reification, which would make this concept a key with which to interpret all kinds of social problems, as well as an intellectual panacea for the difficult work of analysing inequalities. Operationalising and measuring the concept have also caused controversy. The recent initiative by the World Bank to compile an Integrated Questionnaire for the Measurement of Social Capital (SC-IQ) was clearly intended to facilitate more standardised and comparative research on the technological and methodological levels (Grootaert *et al* 2004). Researchers in the field of social capital at large are conscious of the potentialities but also of the dangers inherent in their specific approaches. In their study on the links between social capital and community-level influences on HIV infection in a South African mining community, Campbell *et al* (2002) warn against the ambiguity, the complexity and even the contradictory nature of their findings. They come to the following conclusion:

The interface between sexual health and social capital is an area that defies easy generalization, and one where researchers need to proceed with caution (Campbell *et al* 2002: 51).

This must definitely be borne in mind in our own analysis.

2. Methods

Our data is based on oral interviews with a stratified random sample of 310 pulmonary TB patients. Researchers of the CHSR&D of the University of the Free State conducted these interviews during the period October 2001 to March 2002 (Heunis 2004: 162-164; Matebesi 2004: 94-98). Geographically speaking, the respondents come from three health sub-districts of the Free State province, namely the Goldfields, an urban gold-mining area; Qwaqwa, a predominantly rural previously “independent” black homeland area, and Thaba Nchu, a typical small town in the vicinity of a large informal African settlement. Together the selected areas represent a broad spectrum of socio-economic and socio-cultural conditions and contexts for TB patients. The sample consists of two strata: clinic patients ($n=220$) and hospital patients ($n=90$). The clinic patients were selected randomly from clinics in the selected areas with a high burden of pulmonary TB patients. The hospital patients were selected randomly from the public hospitals ($n=35$)

and the one private (NGO) hospital ($n=55$) in the selected areas. The reason for the larger representation of patients from the private hospital in the sample is of an archaeological nature. In the wake of the actual social transformation of the South African health policy it is essential to document all long-term hospitalisation of TB patients. This specific private hospital, which was closed down in 2002 just as the interviews were completed, was at the time the only hospital in the Free State that offered long-term hospitalisation.

In order to reflect the specific situations of clinic and hospital patients, the CHSR&D developed two separate questionnaires with more or less the same content. Each contains approximately 300 variables, divided into the following clusters: biographical information on the patient; household habitation information; employment, income and medical aid information, and patient career information (knowledge and perceptions of TB; pre-diagnosis and health-seeking behaviour; healthcare contact; treatment by directly observed therapy (DOT) and adherence to this therapy).

We concatenated the data sets of the clinic and hospital patients, as a comparison of the two groups was involved. After having analysed the profiles of the two groups of patients separately,² we selected and recoded the most striking variables, and constructed a number of new variables. There were 65 variables in our concatenated data set. We based our selection of original variables on a “mix” of criteria, of which the most important was that they had to be able to discriminate between the clinic and the hospital patients. Another important criterion was that they had to be useful, so that they could slot into a particular policy calculus (Van Rensburg *et al* 2004a). They had to be reliable, as it made no sense to develop models around variables which, for example, had too great a non-response.

As the questionnaires consisted largely of categorical variables or variables that could be converted to dummy variables without compromising their interpretation, we applied the technique of logistic

2 The two data sets were analysed by a group of graduate students (2003-2004) from the Department of Sociology at the University of Antwerp, as part of their Social Research Methods seminar (cf Constant *et al* 2004). The selection of the 65 variables is based on the research results of this extensive exploratory analysis.

regression analysis (Stevens 2002: 149-154). The standard logistic regression procedure in SPSS 12.0 was used for estimating the model (SPSS 1999: 35-64).

3. Findings

We shall first briefly sketch the profile of the TB patient in the Free State by means of univariate analysis. Then we will use a logistic regression model in an attempt to ascertain the determinants according to which a TB patient seeks treatment in a clinic or a hospital.

3.1 Profile of the TB patient

Males (58.7%) dominate the sample of 310 patients. The modal age group is 35 to 49 years (43.9%). As to marital status, 43.5% are unmarried and 30.3% married. The modal class indicating the highest educational level is grade 7-11 (59.0%); the number of respondents with matric (grade 12) or a higher qualification is small (12.6%). The average household size (including the respondent) is 4.41, though many are much larger. In one out of two households (50.0%) no-one is dependent on the patient's income for basic necessities; in one out of three households (34.2%) the patient is the main breadwinner. Prior to becoming ill 32.9% of the respondents were unemployed. At the time of the interview (i.e. after the illness had manifested itself) this figure rose to 74.2%, which means that unemployment more than doubled. 32.3% of the respondents lost income due to falling ill with TB, while 24.2% lost income while under TB treatment. The majority of the respondents (58.7%) knew someone who had TB before they themselves were diagnosed. In 23.5% of cases at least one person in the household currently had TB or had had it in the past.

This explorative univariate analysis revealed some broad trends with regard to TB patients in the Free State (and beyond). It mainly concerned the brutally blocked prospects of professionally active people forming part of extended families, or having to work to support families — not necessarily highly skilled people but certainly not illiterate either. It is also important to note that they are submerged in a subculture on which TB has already left its mark: the disease forms part of their daily lives and routine.

Still, TB patients are not a homogenous group. When we enumerate the characteristics of a “typical” TB patient, the chances are that we will generalise too much and take too little account of the very different needs of each patient. More than half of the respondents (58.1%) who were diagnosed with TB said that their health was good or even excellent at the time of the study; only 8.1% said that their health was poor. The study covered a cross-section of patients, and interviews were conducted with them in various phases of the illness process. One was recovering; another’s prospects were very bleak. 29.0% described their health at the time of the interview as “Much better than one year ago”; 11.0% as “Much worse than a year ago”. We did not only note differences in subjective perceptions: there were major differences in analysing their ability to perform the activities of daily life (ADL scores). With regard to examples of “light” activities (getting out of bed into a chair; preparing and cleaning vegetables when sitting, and so on), the majority (69.4%) said they were not limited at all; 14.2% were severely limited. Other aspects required a cautious, nuanced approach. The respondents were asked: “In terms of your normal life, to what extent has your illness with TB affected ...?” The response categories are arranged in descending sequence below, indicating how many chose a specific category of affectedness by their illness:

- 1) Ability to carry out family obligations: Yes=209 (67.4% of 310);
- 2) Ability to work: Yes=200 (64.5%);
- 3) Independence: Yes=153 (49.4%);
- 4) Status in the community: Yes=132 (42.6%);
- 5) Relationship with friends: Yes=95 (30.6%).

There were major differences in the ways in which the respondents combined these response categories: 53 respondents indicated all categories, 51 four categories, 56 three categories, 55 two categories, 30 one category and 52 no category (for 13 respondents the information for at least one of the variables was missing). It was difficult to compare respondents at one end of the spectrum with those at the other. TB could either be experienced as an “earthquake” disrupting all spheres of social life, or as an unfortunate event hardly causing a ripple — and these opposing attitudes were found in equal measure.

One variable that appeared very significant in many respects was the patients' medical status. There were four categories: new patients in the intensive phase of treatment; new patients in the continuation phase; re-treatment patients in the intensive phase, and re-treatment patients in the continuation phase. The distinction between new and re-treatment patients is an indicator of the severity of illness, since a re-treatment patient is at a higher risk of contracting multi-drug-resistant (MDR) TB strains. Table 1 indicates how patients were divided according to their medical status and the locus of their treatment. 31.8% of the clinic patients and 61.1% of the hospital patients had re-treatment status. Most new TB patients go to a clinic for treatment. In absolute figures re-treatment patients also often turn to clinics, but in comparison with new patients, they are more often hospitalised. However, when it comes to channelling TB patients to a place in the healthcare system, other factors also play a role.³

Table 1: Patients according to medical status and locus of treatment

	Clinic	Hospital	
New patients – intensive phase	71 (32.3)	14 (25.9)	85
New patients – continuation phase	79 (35.9)	7 (13.0)	86
Re-treatment patients – intensive phase	33 (15.0)	15 (27.8)	48
Re-treatment patients – continuation phase	37 (16.8)	18 (33.3)	55
	220 (100)	54 (100)	274

Pearson $\chi^2=17.769$; $df=3$; $P < .000$

3.2 Logistic regression model

The dependent variable in the model is the place (or setting) of treatment of the TB patient. Patients either visit clinics or are hospitalised. Treatment in a clinic is ambulatory, while hospital treatment implies accommodation in the institution. The dependent variable of locus is

- 3 In the logistic regression model that we developed further, we did not include the variable medical status, because of missing data from 36 of the 90 hospital patients. The logistic regression procedure follows a listwise deletion approach, and inclusion of the variable would thus have meant that we would have lost more than a third of the hospital patients in the model.

thus dichotomous with two classes: 1=Hospital and 0=Clinic. After some exploratory analysis of the 65 variables in the data set we included 7 independent variables (covariates) in the model. Five of these (area, risk, income loss, effect, social capital) were recoded to dichotomous variables. The indicator for social capital is based on questions about satisfaction with relational support and has two possible classes: durable or volatile social capital (see 4.2.7). The sixth variable, employment, initially had five classes, which we recoded to three, namely: formally employed, informally employed and unemployed. The three original classes of the seventh variable, first contact, were retained. The steps followed in transforming the information from the questionnaires into covariates are indicated in Table 2.

The model fulfils the requirements of the maximum-likelihood method (see Table 3). The model test is thus significant ($< .000$), and Nagelkerke pseudo R^2 gives a large proportional reduction in errors: 32%. Moreover, the model classified 77.6% of the patients correctly with regard to the locus of clinic or hospital. Table 3 further indicates that employment, income loss, social capital and first contact are significantly different from 0 (using a significance level of 0.05). Strictly speaking, this is not the case for the variables of area and risk. The variable area was, however, included in the model, since both the degree of fit and the model's ability to accommodate all the clinic and hospital patients in two separate groups appeared to be better than with another model omitting this variable. The variable of risk was included in the model because it lies quite close to the postulated significance level and moreover because the 95% confidence interval largely encompasses the value 1 (0.97-3.23).

Table 2: Covariates of the binary logistic regression model

Questionnaire	Original categories	Frequencies original categories	Name indicator variables	Dummy categories	Frequencies dummy categories
Where did you live until 16 years old?	1 = city 2 = town 3 = rural area or farm	9 170 130 Total 309	area	1 = rural area or farm 0 = city or town	130 179 Total 309
Have you ever worked in a mine?	1 = Yes 2 = No	81 229 Total 310	risk	1 = mine, jail, or both 0 = neither in mine nor jail	111 199 Total 310
Have you ever been in jail?	1 = Yes 2 = No	52 258 Total 310			
Were you employed prior to becoming ill with TB?	1 = full-time, formal 2 = part-time, formal 3 = informally employed 4 = self-employed 5 = unemployed	165 14 21 8 102 Total 310	employment(1)	1 = formally employed (full-time, formal; part-time, formal; or self-employed) 0 = otherwise	181 114 Total 295
Did you lose income due to falling ill with TB, t_e because you could not work as before?	1 = Yes 2 = No	100 209 Total 309	employment(2)	1 = informally employed 0 = otherwise reference category "unemployed"	20 275 Total 295
			income	1 = Yes 0 = No	100 209 Total 309

Table 2: Covariates of the binary logistic regression model (continued)

Questionnaire	Original categories	Frequencies original categories	Name indicator variables	Dummy categories	Frequencies dummy categories
In terms of your normal life, to what extent has your illness with TB affected you regarding <ul style="list-style-type: none"> • your independence • your ability to carry out family obligations • your relationship with your friends • your status in the community • your ability to work 	0=Not at all 1=Yes	0 1 Total 154+153=307 89+209=298 173+95=268 173+132=305 76+200=276	effect	1=effect (5x, 4x or 3x effect) 0=effect (0x, 1x or 2x effect)	160 137 Total 297
Which healthcare facility/provider did you first contact when you experienced symptoms of what you knew to be TB?	1=Private doctor 2=Clinic/community health centre 3=Hospital	110 159 56 Total 305	first contact	1=Private doctor 2=Clinic/community health centre 3=Hospital	110 159 56 Total 305
The network of family members, friends and neighbours to whom you have ready access can be an important factor in restoring and maintaining good health. Indicate your present level of satisfaction with each source of support: <ul style="list-style-type: none"> • spouse or partner • parents • other family members (including children) • friends • neighbours or community members 	0=no support 1=stable support	0 1 Total 195+114=309 112+196=308 65+242=307 88+219=307 74+232=306	social capital	1=durable social capital (5x or 4x stable support) 0=volatile social capital (0x, 1x, 2x or 3x stable support)	138 171 Total 309

Table 3: Logistic regression on locus of treatment in clinic (ref = hospital)

	Estimate (B)	Sig	Exp (B)
Lived until 16 years old (ref=rural)	-.469	.149	.626
At risk (ref=mine and/or jail)	.574	.061	1.775
Employment (ref=unemployed)		.031	
Formally	-.102	.793	.903
Informally	1.445	.023	4.242
Lost income? (ref=yes)	1.166	.002	3.210
Effect of TB on life? (ref=great effect)	.646	.049	1.908
First contact (ref=hospital)		.002	
Private doctor	1.643	.020	5.171
Clinic/community health centre	2.226	.001	9.264
Social capital (ref=durable social capital)	-1.046	.001	.351
Constant	-3.210	.000	.040

Model $\chi^2_{(9)}$: 73.1; sign.: 0.000

Nagelkerke R^2 : 0.32

% correctly classified: 77.6

3.2.1 Urban/rural antecedent

To some extent the model revealed that illness behaviour of TB patients has antecedents which indicate long before the illness occurs whether the patient will follow the ambulant treatment route at a clinic, or choose hospitalisation. People who have lived in a city or town up to the age of 16 are less willing to receive treatment for TB at a clinic than those who have spent their youth in a rural area or on a farm. This statement holds true regardless of where the person is living when the illness strikes. This relationship thus cannot be explained in terms of the availability and accessibility of facilities. However, a bivariate analysis of the original variable rectifies the finding more significantly than would be indicated by the model. Of the patients who lived in a rural area or on a farm as opposed to in a town or a city, 80.0%, 66.5% and 33.3%, respectively, visited a clinic.

3.2.2 Mine and/or jail antecedent

Whether a person has ever worked in a mine or has ever been in jail, also influences subsequent illness behaviour to some extent. These are social risks that can compromise people for the rest of their lives. The first risk involves bad working conditions, physical exhaustion, inadequate housing and significant danger of infection. The second risk is even worse, as in addition to all the abovementioned negative aspects, there is a social stigma attached to incarceration. Once someone has been associated with these risks, he or she will not easily lose the stigma. Respondents who had never worked in a mine or been incarcerated were 1.78 times more likely to visit a clinic when they contracted TB than respondents who had worked in a mine or been incarcerated, or both. We tested this finding against the original bivariate data. The categories were: 1) never in mine or in prison; 2) in mine but not in prison; 3) in prison but not in mine, and 4) in both mine and prison. Of these groups 75.9%, 74.6%, 53.3% and 40.9%, respectively, were clinic-orientated. The most evident dividing line was prison: people who had been in prison almost invariably “chose” hospitalisation. Those who had been incarcerated and worked on a mine stood the least chance of being treated in a clinic.

3.2.3 Employment

The variables just discussed (area and risk) refer in principle to a phase in the patient's life that is over. Although their indicative value is revealed by the bivariate analyses, they have the least significance of all the variables in the model. The other variables offer information about the phase directly prior to the onset of the illness. The employment variable refers to the patient's employment status just before he or she fell ill. The original five classes of this variable, namely 1) full-time formal employment, 2) part-time formal employment, 3) informally employed, 4) self-employed, and 5) unemployed, needlessly complicated the interpretation of the model, and therefore we ultimately utilised only three classes, namely 1) formally employed, 2) informally employed, and 3) unemployed (as described in Table 2). Globally, the variable indicates a significant relation ($p < .031$) that proves much more significant for informally employed people than for the formally employed ($p < .023$ as against $p < .793$). The odds ratio for the formally

employed was 0.804 as against 3.863 for the informally employed. This implies that the chance of receiving clinic treatment as a TB patient is four times higher for the informally employed than for the unemployed. For the formally employed the odds ratio for clinic treatment was smaller compared with the unemployed. In the bivariate analysis the difference is very marked when patients who were informally employed are compared with all the others. Of the 21 informally employed respondents only 74.4 % were treated in a hospital, compared with 26.7% of the formally employed and 24.5% of the unemployed.

3.2.4 Loss of income

We also considered loss of income. The purpose of this variable was to determine the eventual loss of income rather than to compare the real income of patients prior to the onset of the illness with what they were earning at the time of the study. This loss approach was more reliable, as there were many missing items in the data set with regard to exact earnings at the two points, especially in combination. The variable of income is one of the most significant in the entire model. Patients who do not lose income on account of their illness are more clinic-orientated than those who do. They also have a 3.21 higher chance of being treated in a clinic.

3.2.5 Effect of TB on life

In the study we investigated five spheres or areas that can be affected by TB. We have already indicated the relative importance of these areas and the extent to which they interrelate. The variable in Table 2 indicates in a dichotomous way whether many (5, 4 or 3) or few (2, 1 or none) areas are combined, in other words, whether TB has negatively affected the patient's life in many or only a few areas. This variable is significant in the model. TB causes such a negative effect in many areas for 160 patients and in only a few areas for 137 patients. Patients experiencing inconveniences in many areas are more strongly orientated towards hospital treatment than patients experiencing fewer inconveniences. We mentioned earlier how important the severity of the illness is. The variable of effect is concomitant to the notion of severity of illness as it has a bearing on hindrances with regard to social functioning, not only to biological/organic functioning.

3.2.6 First contact

The sixth variable in the model is first contact, referring to the first medical contact that patients had after experiencing TB symptoms. The model indicates that patients whose first contact is with a private doctor have a 5.17 higher chance of being referred to a clinic than those who go straight to hospital to confirm the diagnosis of TB. Once they have been hospitalised, patients do not readily take to a lower echelon in the health system. Some bivariate analyses give details of the referral channels. Of the clinic patients, 39.1% first visited a private doctor, who referred them to a clinic, while 45.0% went directly to the clinic. For hospital patients the situation was different: 26.7% were hospitalised after being referred by a private doctor, and 66.7% after being transferred by a clinic (or a community health centre). This clearly indicates that clinics and community health centres play a key role in the campaign against TB, not only as places of treatment but also as points from which patients can be transferred to a higher echelon in the health system.

3.2.7 Social capital

The last and most significant variable in the model is the respondents' social capital. Table 2 indicated how the social capital that patients had accumulated was measured. Our calculation is in line with the individual-level approach to social capital. The emphasis is on the resources that people harvest from the networks of more or less institutionalised relationships with other people. The questionnaire requests information about relationships with 1) a spouse or partner; 2) parents; 3) other family members, including children; 4) friends, and 5) neighbours or community members. The variable in the model is the dichotomous version of the addition sum that indicates in how many of these five spheres or areas the respondents experience trust, reciprocity and support. If these are experienced in 5 or 4 spheres, the individual's social capital is described as durable; if in 0, 1, 2 or 3 spheres, the social capital is described as volatile. Each of the five spheres was described as offering stable support in the following number of instances:

- 1) family members including children (but excluding spouse or partner or parents): 242 (78.1% of 310);
- 2) neighbours or community members: 232 (74.8%);

- 3) friends: 219 (70.6%);
- 4) parents: 196 (63.2%);
- 5) spouse or partner: 114 (36.8%).

The spouse or partner obtained the lowest score because only 94 married people and 11 who were living with a partner formed part of the test sample, so that the majority of the respondents could not draw upon this sphere as a source of social capital. The significance of the accumulated social capital in the model is confirmed by bivariate analysis. Of the TB patients with durable social capital only 19.6% were orientated towards hospital treatment, as opposed to 36.8% for patients with volatile social capital. We obtained the same results when we used the original variables (with a range of 0 to 5). The mean for the whole sample was 3.25. The mean for the subgroup of clinic patients was 3.36, and for the subgroup of hospital patients 2.97 (t-test value: 2.79; significance: 0.006). It has already been noted that the hospital patients in fact comprised two groups, namely those from public hospitals and those from a private hospital. If we compare social capital among these three groups, we find the following means: 3.36; 3.14, and 2.85, respectively. Tukey tests show that the means for clinic and private hospital patients differ significantly (Tukey $p < .011$) while those for public hospital patients and private hospital patients (Tukey $p < .484$), or clinic patients and public hospital patients (Tukey $p < .557$) do not. A confidence interval of 95% was used in each case.

4. Discussion

In the course of time the medico-social regimens for the treatment of TB patients have changed many times. This is certainly not unique to TB patients, but it does reflect a general attitude about the place or locus where patients can be treated most effectively. From long-term hospitalisation, preferably in institutions where patients had almost no contact with the outside world, the approach changed to treatment in a familiar environment, in terms of both family and locality, with medical control being practised from a distance. A study undertaken by Mitnick *et al* (2003) in an economically disadvantaged area of Lima, Peru, revealed that community-based outpatient treatment can yield high cure rates even when the prognosis is poor because of chronic,

highly resistant TB, extensive parenchymal damage, and previous exposure to repeated standardised regimens that probably amplified drug resistance:

By moving treatment into the community, it is possible, without compromising the quality of the therapy, to lower costs and reduce the risk of nosocomial spread of multi-drug-resistant TB (Mitnick *et al* 2003: 127).

In recent years this pendulum movement from intra- to extramural treatment of TB patients has been increasingly seen in South Africa. The scope of the private (NGO) hospitals has been reduced, and all capacities have been bundled together to form a district health system, in which the different levels of functional specialisation have been brought into line within a single supportive framework (Van Rensburg 2004b; Gibson 2004). The empirical material in our study indicated that developing such a system answers the needs of many TB patients. In the district health system, clinics function not only as places where TB patients are treated, but also as portals through which seriously ill patients can be referred to higher echelons of the system, such as district and regional hospitals. Private doctors naturally play an important role in the referral system, but it is interesting to note that two-thirds of the TB patients who end up in hospital first passed through the filter of a clinic or a community health centre. Our investigation also revealed that the district health system had its own *modus operandi*. Most patients treated in clinics are new patients, while the majority of hospitalised patients are admitted for retreatment.

Referral of TB patients to the most suitable locus for treatment forms the essence of a TB programme. There is no typical TB patient. There are as many different types of TB patient as there are types of illness behaviour or subcultures of coping with TB. Although the majority of TB patients indicated that their hopes for the future were brutally disrupted by the illness, they differ considerably in other ways. Some are fairly healthy; others critically ill. Some are hardly hampered in the activities of daily life; others cannot do anything for themselves.

Our model deliberately did not take into account hypotheses about the causes or effects of stigmatisation. We approached the study from a different angle, focusing on the factor of social capital (Gilson 2003; Clark 2002; Harpham *et al* 2002). While stigmatisation limits the

alternative behaviours of patients, social capital in fact broadens the scope of their behavioural options. To the extent that TB patients can garner more social capital, and incorporate more resources which are — to use Bourdieu's words — “linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance or recognition” (Portes 1998: 3), they are in a better position to lobby for medical services. However, this also appears to be associated with better communications and accountability mechanisms, with people in well-connected communities being well placed to influence local health services, better informed about them, and more likely to be able to access them (Field 2003; Ziersch *et al* 2005).

Of the 310 respondents only 132 (42.6%) indicated that TB had affected their status in the community. In fact, what was affected was their capacity to carry out family obligations, to work and to be independent. Their status in the community was only fourth on the list. 232 respondents (74.8%) indicated their neighbours and community members as a source of stable support and an important network in restoring and maintaining good health. Only family members scored higher, being indicated by 242 respondents (78.1%). Nevertheless, the role of neighbours and community members in performing DOT for clinic patients was very limited. Nurses were mainly responsible for such supervision (71.4%); only in very exceptional cases did neighbours or community members take charge (3.9%).

The logistic regression model that we tested contained seven variables. We wanted to ascertain which determinants predisposed patients to ambulant treatment at a clinic as opposed to a hospitalisation. Two variables had a bearing on the respondents' life before they contracted TB. The explanatory strength of these two variables is not convincing; however, patients who had lived on a farm or in a rural area in their youth, were more inclined to opt for clinic treatment while, on the other hand, having worked in a mine or been incarcerated were to some extent predictors of a choice for hospitalisation. Life in prison (a total institution *par excellence*) makes a hospital, which also has elements of the total institution, a more logical choice as a locus of treatment. The third variable related to the employment history of patients immediately before the onset of the disease and to whether they were employed or unemployed. The model revealed that this distinction had very

little explanatory strength. However, what was very clearly indicated was that patients who were informally employed and who thus had no form of unemployment insurance were hospitalised much more quickly than others. When informally employed people fall ill and can no longer meet their daily needs, a hospital is clearly a safer place than a clinic, where they would have neither a roof over their heads, nor food to eat. The fourth variable concerned the extent to which patients lose income on account of their illness. Patients who lose no income are strongly clinic-orientated, but those who do lose some income or, like the informally employed, forfeit their only source of income, are much more hospital-orientated. The fifth variable concerned the capacity of patients to continue functioning in society and carrying out their daily activities. Patients who are not unduly limited by their illness are happy with clinic treatment, but patients who are incapacitated on many levels prefer a hospital. The sixth variable concerned the patients' first place of contact for entering the health system. Private doctors are important in referring patients to clinics and hospitals, but by far the majority of patients visit a clinic of their own accord at the first sign of illness. Clinics and community health centres *are* thus pivotal in the campaign against TB. Most patients first go to a clinic, even if they are later referred to a hospital. The seventh variable concerned the (non-)accumulation of social capital. Patients who have durable social capital are strongly clinic-orientated, while those with limited social capital are more hospital-orientated. TB drags patients down into a whirlpool from which they have only a very dim view of the future, but those who have durable social capital have a better opportunity to develop illness behaviour characterised by the perseverance needed to continue their treatment to the very end and by rational handling of the many uncertainties that occur during the recovery period.

Accumulating social capital is a prerequisite for optimal use of all the opportunities offered by the TB control programme in the Free State. The means for implementing the programme are limited, and thus the provincial government, those responsible for the institutions of care, and the healthcare workers themselves are very tempted to re-frame their failure to provide access to treatment as the patients' failure to adhere to prescribed drug regimens. TB patients, especially the poorest of the poor, are warned to "clean up their acts for their own good and

for the public good” — in the words of Farmer (2003: 165-166). The fact that social capital was indicated in our study as a very important instrument in combating TB should provide the impetus for ensuring that TB programmes are much more attuned to the needs of TB patients but at the same time also to the full range of their human capabilities of TB patients. TB patients must be able to turn to a readily accessible and integrated network of care in which the various structures (primary health care, clinics, hospitals, drug suppliers, laboratories, and so on) function in complementary synergy to ensure continuous care.

The importance of community TB care has been recognised worldwide in the campaign against TB (Torkington 2000; Dudley *et al* 2003; Verbergt 2004). The results of our study indicate that the stigmatisation of TB patients in their own environments has been overestimated, and that they actually have access to a wide range of resources, a reservoir of social capital, that can make their illness behaviour more persistent, rational and effective. In the Free State TB control programme, clinics and community health centres form the focal points. These settings are not peripheral to, but in the centre of each local community, the *Gemeinschaft* of the patients, who either visit the clinics directly or are referred there by community organisations, which actually function as meta-channels for the dissemination of health information (Stephens *et al* 2004). At the same time family members, local liaison people, private doctors, traditional healers, field-workers and volunteers promote trust in the TB control programme, thus strengthening the patients' social capital. They take responsibility for helping to ensure that TB patients are placed in whichever position in the district health system can best meet their needs, depending on the severity of their illness and the capacity of their household and environment. The study also indicated that it is very difficult to ensure the local realisation of the most operational aspect of a TB control programme, namely the application of DOT. To ensure that DOT is generally accepted, in the patient's neighbourhood, it is essential that it should develop from a uniform to a customised approach (Mack *et al* 2003). Our study of social capital as a determinant of behaviour, supports this. In the implementation of DOT strategies, it is not only the expertise of health professionals that must be taken into account. The knowledge, experience

and practical capabilities of both patients and health professionals have to be brought together in order to arrive at mutually agreed goals (Bissell *et al* 2004). Only then will the patient no longer be blamed for non-compliance with treatment, because the concept of concordance will have been accorded its rightful place in the global campaign against TB.

5. Conclusion

Astonishment at the many faces of TB was the point of departure of our study. The TB patients in the Free State who were the subjects of our study are deprived on many levels and their prospects for the future are disrupted. Even so, we encountered major differences between them, undoubtedly because of our cross-sectional approach, which meant that patients in widely divergent phases of the illness were included in the same sample. But the differences were also more profound than this: patients' medical status, functional capacities, cultural backgrounds, and the extent to which the illness disrupted their lives all led to many different forms of illness behaviour and created just as many types of patient.

In our analysis of the data we paid special attention to the determinants predisposing TB patients either to ambulant treatment in clinics, or to treatment in hospitals, a divide that has considerable social and policy relevance in the campaign against TB in South Africa. In the series of significant determinants, social capital takes priority. Even if we are very cautious in our interpretation of this determinant, it is clear that TB patients who can rely on an extended network of relationships are much more committed to clinic treatment. The relationships that we took into account when operationalising social capital operated on various levels: among family members and friends, in the work environment or the local community, and so on.

With the multi-level approach which is inevitable when one studies social capital, we focused on the resources that TB patients can harvest from their local communities and, as extensions of these, from primary health care facilities. The referral of TB patients to community health centres and clinics generally occurred quite naturally and spontaneously. Clinics functioned not only as loci of treatment, but also as points from which patients were referred to higher echelons in the health system.

The dynamic of the referral of patients to the most adequate and humane places of treatment implied that the many activities directed at TB control have to be firmly embedded in a strong general healthcare system. More than ever before, aid givers feel the need for templates that can map out the specific needs and, in fact, the full range of human capabilities of TB patients in the local communities and the health districts and sub-districts of the Free State, so that the concomitant problems can be addressed by means of effective, customised solutions.

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