

# Psychology and adherence of tuberculosis patients: Do illness perceptions predict poor adherence to TB management?

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Received: 3rd December, 2014. Accepted: 23rd January, 2015. Published: 3rd March, 2015.

## Abstract

To quantitatively explore illness and medication perceptions of tuberculosis patients and to examine their impact on patient adherence to medical management. A questionnaire eliciting illness and medicines perceptions and socio-demographic data was designed. TB patients in three TB services in North East London were recruited and completed the questionnaire. Further data, including the outcome measure of clinic attendance, were collected from clinical notes. Bivariate data analysis was conducted and variables most associated with the outcome measure were entered for regression analysis. Recruited patients were characteristic of TB patients in North East London ( $n = 109$ ). Patients reported perceptions of short timeline, greater personal control and treatment control over their illness, somewhat incoherent and negative emotional perceptions of their TB, and general perceptions of the benefit of their medicines. Correlations were observed between illness and medicines perceptions, and with self-reported and outcome adherence measures. Regression analysis identified that patients speaking English as a first language and patients with negative emotional representations were more likely to miss scheduled clinic appointments. Illness perceptions may present modifiable factors for use in interventions designed to promote TB patient adherence. Further research needs to clarify the relationship between illness/medication perceptions and adherence.

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**Keywords:** tuberculosis, illness perceptions, adherence, psychology, IPQ, medicines  
**ISTJN 2015; 5:56-70.**

## 1 Introduction

Tuberculosis (TB) is an infectious mycobacterial disease of public health concern. Transmission can occur when an individual with pulmonary TB exhales droplets containing TB bacilli which are inhaled by another individual, usually a close contact. TB is a curable disease with highly efficacious and cost-effective drug treatments, a range of diagnostic techniques, and preventive measures including chemoprophylaxis and vaccination. However, it is estimated that one-third of the population globally is infected with TB resulting in an estimated 8.9 million deaths in 2004 (WHO, 2007). This implies that the current approaches have not been successful. The long duration of treatment, upward of six months, can result in patient non-adherence; consequences include primary bacterial drug resistance. Treatment of resistant TB is more complex, expensive, less efficacious and not as well tolerated as first-line treatment (White & Moore-Gillon, 2000). Directly observed treatment (DOT) of TB treatment aims to improve adherence but is advocated in the United Kingdom - a low TB burden country - only for individuals at high risk of non-adherence (NICE, 2006).

Although patient non-adherence is essentially behavioural, attention paid to the psychological aspects of TB is relatively scarce; evidence is mostly qualitative. For example, Poss (1998) highlighted a number of misconceptions about TB amongst Mexican migrant farm workers. One opinion was expressed that TB was transmitted by "just being around someone who has it. Or drinking out of their glass. Or eating off their plate". Avoidance strategies were suggested which included not smoking, staying out of air conditioning, not going between hot and cold weather, being careful of the climate you live in and work in, not getting too chilled, and not being around too much dust and smoke. In relation to the social implications of TB, participants suggested stigma associated with the disease: "most people are afraid to talk about it. If other people find out they have it, then they won't want to be around them any more". Social stigma towards TB was also recognised in research in Pakistan (Liefoghe *et al.*, 1995; Liefoghe & Muynck, 2001). These studies identified perceptions of stigma and social isolation particularly amongst females. The perception of stigmatisation of TB was found to be related to default from treatment.

Similarly Nnoaham *et al.* (2006) used in-depth interviews amongst African patients attending a TB clinic in Hackney, London. TB stigma was evident amongst this cohort and worsened by the association with HIV. Half the patient sample also denied diagnosis of TB.

The scientific literature demonstrates the impact of how TB disease is perceived by defined groups which make up society and implies a psychological component. There have been calls for TB research in adherence involving a theoretical basis that has previously been lacking (Sumartojo, 1993). However, the course of TB disease is patient-specific in terms of how the disease progresses in its various forms and its management. Any psycho-social modelling should account for this dynamic element with the ultimate aim of tailoring management of TB to incorporate both medical and psycho-social components.

Through the Self Regulatory Model of Illness Representations (SRM), Leventhal *et al.* (1992) described that an individual's coping strategy in response to a health threat, such as TB, is informed by their perceptions of that health threat. The chosen coping strategy results in a particular outcome accordingly. However, the dynamic nature of the model allows for changes to how the individual perceives the health threat, their coping strategy and ultimately the outcome. The theory of the SRM has been operationalised using the Illness Perception Questionnaire (IPQ) (Weinman *et al.*, 1996) which was later revised with some additional components (Moss-Morris *et al.*, 2002). As such, the revised IPQ (IPQ-R) consists of constructs measuring perceptions of illness timeline (cyclical and acute/chronic), consequences of illness, causes of illness, treatment of illness, illness identity, illness coherence (making sense of illness), personal control and emotional representations.

The IPQ-R has been used in a number of studies to address non-adherence. Johnson and Folkman (2004) investigated illness perceptions amongst 107 HIV-positive patients and assessed self-reported adherence including reasons for reported non-adherence. They identified association between adherence and illness perceptions such that less adherent patients perceived greater consequence of their disease and expressed negative emotional representations. In a larger study, Butler *et al.* (2004) used the emotional representations component of the IPQ-R along with the IPQ inventory to investigate illness perceptions amongst patients treated for hypertension ( $n = 519$ ). Using a self-reported adherence scale they identified association between adherence and four components of illness perceptions - emotional representations, consequences, and personal and treatment control. Hussain *et al.* (2008) investigated illness perceptions amongst TB patients in Pakistan. A relationship between depression/anxiety and negative illness perceptions was identified but the authors acknowledge the need to account for adherence as a potential confounder.

Medicines perceptions have also been investigated in relation to adherence. For example, Horne and Weinman (1999) have suggested that a cost-benefit assessment is made by an individual regarding their personal beliefs in the necessity of medication and concerns over its potential adverse effects. This assessment then influences adherence to medication. The Beliefs about Medicines Questionnaire (BMQ) was developed by Horne and colleagues to operationalise this theory (Horne R, Weinman J, Hankins M, 1999). Similarly, Duggan developed the Perceived Utility of Medicines scale (PUM) using grounded theory from an inventory of fifty survey items (Duggan & Bates, 2000). The PUM consists of two scales

that address the perception of medicines benefit and harm.

This study sought to quantitatively explore illness and medication perceptions and to examine the relationship between these perceptions and patient adherence to medical management. This research was conducted to begin the process of identifying the most important medical, psychological and social elements that impact on TB patient management and subsequently whether these could inform an intervention to improve treatment outcomes.

## **2 Methods**

### **2.1 Setting**

The three TB services in the Northeast London Primary Care Trusts (PCTs) of Newham, Tower Hamlets and City and Hackney were targeted for patient recruitment. These services served neighbouring PCTs and were chosen as, together, they represented the highest incidence of TB in London and they were broadly reflective of the various ethnicities that are prevalent in UK TB cohorts. Ethical approval for the study was granted by the East London and The City Health Authority research ethics committee.

### **2.2 Procedure**

A convenience sampling technique was adopted and patients were recruited by the principal investigator (TR) from waiting areas in outpatient TB clinics before scheduled appointments. Patients were introduced to the principal investigator by clinic staff and were given a brief description of the study with a study leaflet. Data collection took place for 18 months from March 2004. Following collection, data were anonymised.

### **2.3 Inclusion criteria**

The following inclusion criteria were used: patient aged 18 or over, proficiency in English, Urdu, Bengali or Turkish (the three most common languages for which questionnaires were translated (Rennie *et al.*, 2008)), diagnosis of TB, and prescription of anti-tuberculous medication; patients were required to have been taking medication for at least one week for them to have experienced TB medicines use. In addition, patients were excluded if they were considered by clinic staff to be unfit for research participation; clinic staff were consulted

before each patient was approached with valid reasons sought for exclusion, for example, patient too unwell to participate.

## 2.4 Questionnaire and data collection

Patient medical notes were consulted for suitability of patient participation and data extracted that were relevant to the study following patient recruitment. In addition, a self-completed questionnaire was designed for the purposes of data collection. The questionnaire included two sections in order to clearly distinguish between TB-related items (Section one) and other patient-related information (Section two). Section one incorporated the IPQ-R, the PUM and a self-reported adherence question, and section two incorporated questions elucidating various socio-demographic details that were not routinely available in clinical notes (Figure 1).

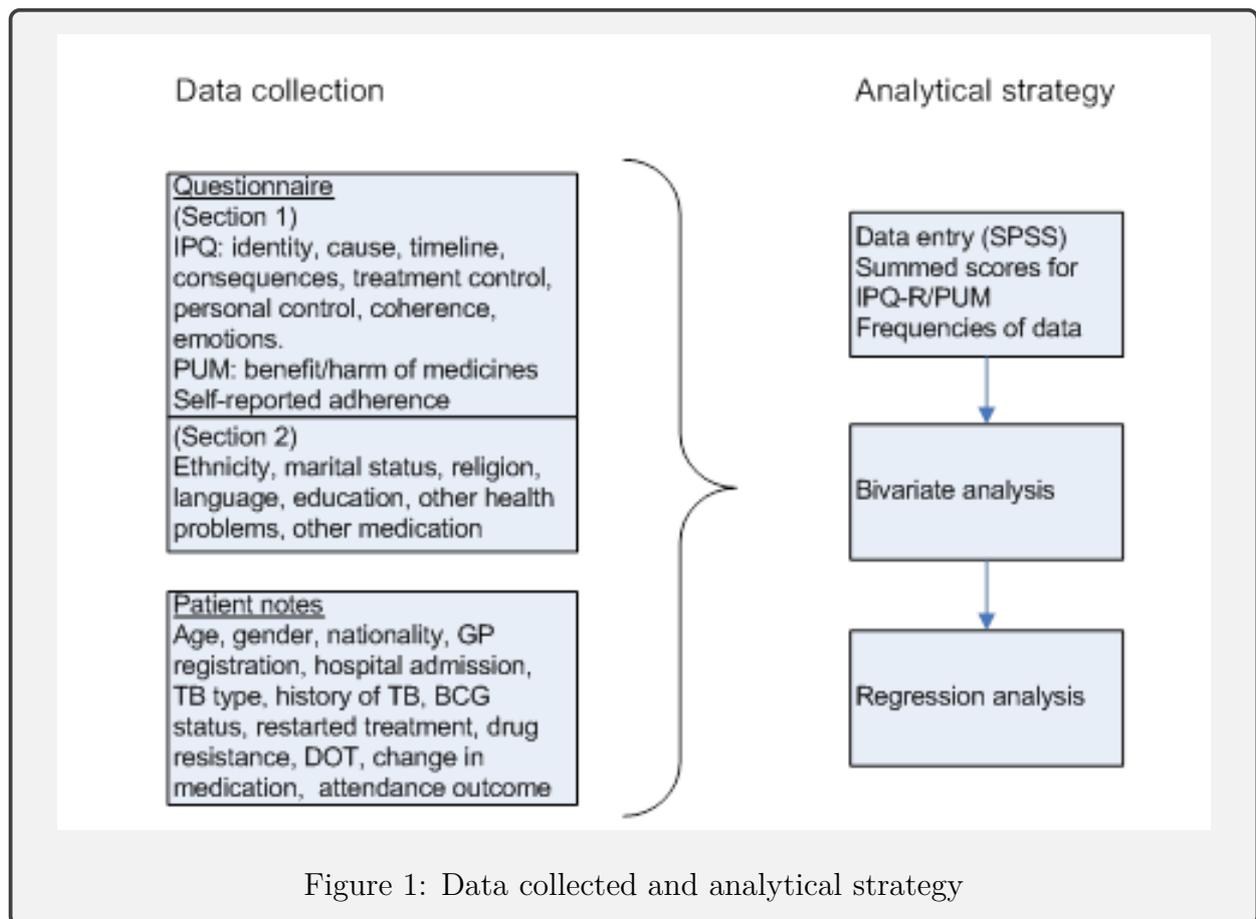


Figure 1: Data collected and analytical strategy

## **2.5 Illness and medicines perceptions, and self-reported adherence (questionnaire Section 1)**

The SRM was operationalised using the IPQ-R (Moss-Morris R & Weinman, 2002). However, the cyclical timeline component was not used as a treatment outcome ('treatment completed' or 'cure') is reached in the vast majority of cases without complication. A dichotomous response format was used for the symptom identity scale and two symptoms more specific to TB - fever and sweats - were added to the generic list. In common with other research using the IPQ inventories in previously unexplored disease conditions, the open question "In your opinion, what caused your tuberculosis?" was used to elicit patient perceptions of causal attributions of TB (Heijmans *et al.*, 1999; Helder *et al.*, 2002). The term 'tuberculosis' substituted the generic term 'illness' in the original IPQ-R, as suggested by the authors (Weinman *et al.*, 1996).

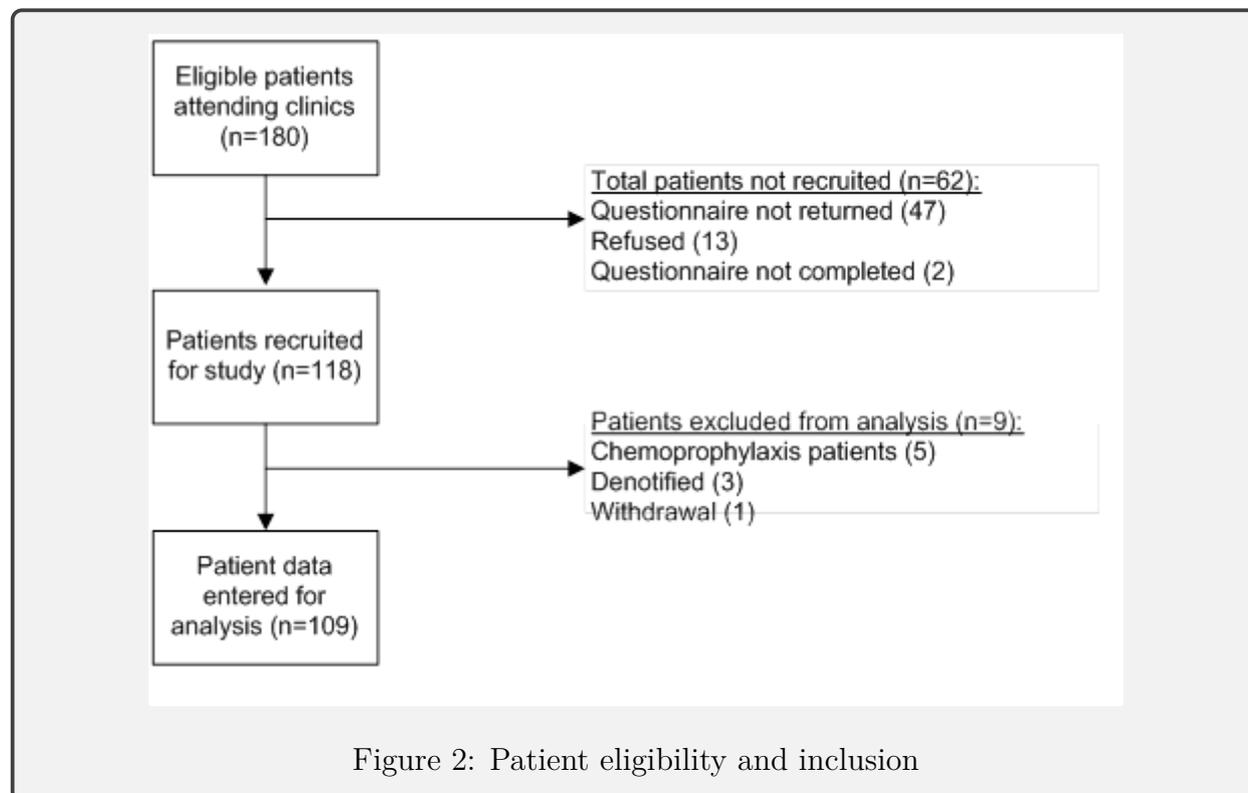
The PUM, consisting of the three-item Perceived Benefit of Medicines (PBM) scale and the four-item Perceived Harm of Medicines (PHM) scale, was used to elicit medicines perceptions.

Likert scale responses (strongly disagree, disagree, neither agree nor disagree, agree, strongly agree) were used for the majority of sub-scales (Timeline, Cure/Control, Consequences, Coherence, Emotional Representations, PHM and PBM).

Self-reported adherence was measured using the question "Have you missed any pills in the last week?" (Haynes & McDonald, 2002). A dichotomous response (Yes/No) was used to elicit this.

## **2.6 Outcome measure (patient notes)**

The main outcome measure used was the number of times patients 'did not attend' (DNA) a scheduled clinic. As some patients would have had extended durations of illness due to drug-resistance or concomitant disease, only DNAs within the first six months of treatment were considered; six months is the standard duration of treatment of pulmonary TB without complications. DNAs were recorded in medical notes. TB patients attended similar scheduled appointments for diagnosis, treatment initiation and follow-up; DOT TB patients attended TB Services more regularly but their attendance was documented separately in nursing notes and this data was not extracted for the study.



## 2.7 Patient-related variables

A number of items elucidating patient details were incorporated into the questionnaire including ethnicity, marital status, religious status, language, age and level of last education, illness besides TB and medication besides TB medication. Further demographic and clinical variables were elicited from patient medical and nursing notes (Figure 1).

## 2.8 Data handling and statistical analysis

Data were coded and entered into a data-frame in SPSS<sup>®</sup> (version 12.0). Summed scores were calculated for the various scales and used in bivariate analysis. Statistical association was sought using the following tests depending on data type: Pearson chi-squared test ( $\chi^2$ ), Mann-Whitney test ( $U$ ), Kruskal-Wallis test ( $H$ ), and Pearson correlation ( $r$ ). Independent variables were entered into multiple regression analysis based on greatest correlation with the dependent variable. Due to the exploratory nature of this study, stepwise regression was chosen as the method for variable entry.

Table 1: Reliability of IPQ-R and PUM scales

Scale		Mean	Variance	S.D. <sup>‡</sup>	$\alpha^{\ddagger}$
IPQ-R	Acute/chronic timeline (items 1-5, 18)6	14.13	13.60	3.69	0.64
	Consequences (items 6-11)6	18.69	25.29	5.03	0.77
	Personal Control (items 12-17)6	21.22	13.54	3.68	0.62
	Treatment cure/control (items 19-23)5	20.27	7.26	2.69	0.71
	Coherence (items 24-28)5	16.47	15.22	3.90	0.75
	Emotional reps. (items 33-38)6	17.85	36.358	6.03	0.90
PUM	PHM (4 items)	11.42	13.524	3.68	0.73
	PBM (3 items)	11.85	4.145	2.04	0.66

<sup>‡</sup>Standard deviation; Cronbach's alpha coefficient

### 3 Results

Reliabilities for the final scales used further in analysis are reported in Table 1.

Table 2: Baseline characteristics of patient sample by treatment clinic

Baseline variable	Hackney ( <i>n</i> = 42)	Tower ( <i>n</i> = 27)	Hamlets Newham ( <i>n</i> = 40)	Total ( <i>N</i> = 109)	Statistical significance
Mean age (years)	33.7	31.0	35.7	33.8	
Gender (% male)	54.8	61.5	60.0	58.3	
Country of birth (% UK)	28.6	16.0	35.9	28.3	
GP registration (%)	92.7	96.2	90.0	92.5	
History of TB (%)	2.4	15.4	5.0	6.5	
Family history of TB (%)	24.4	16.7	12.5	18.1	
Referral (%):					<i>p</i> < 0.001*
A&E	56.3	8.3	15.8	27.7	
GP	15.6	66.7	39.5	38.3	
Other	28.1	25.0	44.7	34.0	
Hospital admission (% admitted)	69.0	50.0	43.6	55.1	
Site of infection (% pulmonary TB)	57.1	50.0	45.0	50.9	

\*Pearson chi-squared test for association ( $\chi^2$ )

Abbreviations: A&E=Accident and Emergency, GP=general practitioner,

Other=other hospital or hospital department, CoB=country of birth, UK=United Kingdom.

### **3.1 Demographics of recruited patients**

Of the 180 eligible patients, 118 were recruited for the study resulting in a 65.6% response rate (Figure 1). Nine patients were subsequently found to be ineligible: Five patients were being treated for latent TB, three patients were 'denotified', meaning that the initial diagnosis of TB was incorrect, and one patient was initially enrolled in the study but later withdrew. In the recruited sample ( $n = 109$ ), similar proportions of patients were recruited from the three participating clinics (Table 2). Mean patient age was 33.8 years and more male patients (58.3%) were recruited than female. The minority of patients were born in the UK (28.3%) and most patients were registered with a general practitioner (GP, 92.5%). These demographics are similar to those for the TB population in the three PCTs (mean age = 23.7 years, male = 56.7%, UK born = 18.1%, 2002-2006, unpublished data, NE London TB Network). No differences in baseline characteristics between recruitment clinics were observed except for referral route (Table 2). Patients attending Hackney, Newham and Tower Hamlets clinics were more likely to have been referred by Accident and Emergency services (A&E), GP and another hospital or hospital department respectively. This likely related to Hackney TB Service being based at a hospital site with A&E, Newham TB Service being based in a community setting, and Tower Hamlets TB service being a tertiary referral centre.

### **3.2 Responses to IPQ-R, PUM scales and self-reported adherence**

In terms of identity, the most frequently cited symptoms of TB were 'loss of strength' (99%), 'weight loss' (64%), and 'sweats' (60%). The least frequently cited symptoms were 'wheeziness' (23%), 'sore throat' (20%), and 'sore eyes' (14%). Perceptions of cause were categorised by the authors into similar groups. A total of 136 citations of cause were reported, the most common being contact with another person or group of persons (25%), unknown causes (23%), and environmental causes (9%).

In this cohort, considering the summed scores of scale responses, TB patients appeared to have great confidence in their treatment, medicines and own control (Table 3: Treatment cure/control, PBM, personal control). Patients were less polarised in responses to other scales although overall they had perceptions of long timeline of illness, significant consequences of illness, coherence of their illness, emotional responses to illness (for example depression and anxiety) and perceptions of medicines harm.

One hundred patients self-reported their medication adherence; 19 of these patients (19%) admitted to missing taking TB medication in the previous week.

Table 3: Sample responses to IPQ-R and PUM scales by score

Scale	Overall disagreement	Neither agree nor disagree	Overall agreement
Acute/chronic timeline e.g. My TB will last a short time	57.4	7.4	35.2
Consequences e.g. My TB has major consequences on my life	23.4	6.4	70.2
Personal control e.g. There is a lot which I can do to control my symptoms	3.1	1.0	95.9
Treatment cure/control e.g. My treatment can control my TB	0	0	100
Illness coherence e.g. I have a clear picture or understanding of my condition	22.4	0	77.6
Emotional representations e.g. When I think about my TB I get upset	33.7	4.1	62.2
PBM e.g. My medicines relieve my symptoms	2.9	0	97.1
PHM e.g. The side effects are another form of disease	30.6	8.2	61.2

Percentage of summed scores above (overall agreement) or below (overall disagreement) the midpoint; midpoint = 7.5 for 3-item scales, 10 for 4-item scales, 12.5 for 5-item scales, 15 for 6-item scales

### 3.3 Adherence outcome: Patient attendance to scheduled clinic

Attendance records were available for all patients ( $n = 109$ ). Forty-eight patients (44.0%) missed at least one scheduled clinic appointment (Range 0-8; Mean=0.92; standard deviation=1.44).

### 3.4 Construction of regression model

Independent variables that had the strongest associations with the dependent variable, number of patient DNAs, were entered for regression analysis. These variables included patient gender (male/female), English as a first or second language (first/second), drug-resistance of patient TB (any resistance: yes/no), perceptions of consequences (score range: 6-30), perceptions of emotional representations (score range: 6-30), perceived harm of medicines (PHM, score range: 4-20), whether patient reported other medicines besides TB-related (yes/no), and self-reported adherence (yes/no). A model consisting of four variables was found to explain 35.8% variance (Table 4). Each of the four variables entered into the model accounted for significant amounts of variance: English as a first or second language explained 13.3% variance, emotional representations 12.9%, self-reported adherence 5.2%, and gender 4.4%. This suggested that patients who spoke English, male patients, patients reporting negative emotional perceptions of TB, and patients reporting non-adherence were more likely to exhibit poorer clinic attendance. All model assumptions were met including demonstration

of independence of errors (Durbin-Watson test), no evidence for multicollinearity (based on no Pearson correlations between predictor variables, and acceptable variance inflation factor and tolerance levels), evidence of homoscedasticity and linearity, and normal distribution of errors. In addition, no cases were reliably identified as outliers.

Table 4: Final regression model

	<i>B</i>	SE( <i>B</i> )	$\beta$
[Step 4]			
Constant	0.708	1.244	
Language	1.236	0.370	0.336**
Emotional Repts.	0.096	0.025	0.369***
Self-reported adherence	-1.071	0.425	-0.245*
Gender	-0.705	0.323	-0.215*

Note  $R^2 = 0.13$  for Step 1;  $\Delta R^2 = 0.13$  for Step 2;  $\Delta R^2 = 0.05$  for Step 3;  $\Delta R^2 = 0.04$  for Step 4; \* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$ .

## 4 Discussion

The current study gives an insight into how TB patients perceive their illness and medical treatment, adherence to medical management, and the factors involved in likelihood of attendance to TB clinic.

In demographic terms, the cohort was broadly representative of TB patients in North East London. In relation to the general population, this disease group is relatively young with slightly higher incidence amongst men. It is a disease that predominantly affects people in the UK who have originated from countries of high TB prevalence. Another typical observation of UK TB patients is that approximately half of patients exhibit extra-pulmonary TB, that is, TB affecting parts of the body besides the lungs (HPA, 2008); the study sample was reflective of this.

Analysed as a cohort, TB patient responses to the various psychological scales (IPQ-R and PUM) appeared to suggest great confidence in treatment and personal control over their illness although responses were more equivocal regarding other perceptions such as illness timeline. This may be explained by there being standard and established efficacious drug treatments for TB that will very likely result in treatment success although the duration of treatment, in relation to many other curable infectious diseases, is long. Almost certainly TB patients will have had this explained to them by TB health professionals.

The main outcome measure used was the number of times a patient 'did not attend'

(DNA) a scheduled clinic appointment. This was used as a continuous measure in analyses to obviate the need to decide upon a cut-off point at which non-attendance was deemed clinically significant. The limitation to this is that the current study did not identify a point at which non-attendance was clinically significant. However, in demonstrating relationships with a number of other factors this outcome measure appeared to be justified. Whitmarsh and colleagues (Whitmarsh *et al.*, 2003) sought to identify psychological antecedents of poor attendance in cardiac rehabilitation and decided upon using a dichotomous measure based on local observation of attendance. In the current study no formal analysis could suggest at what point attendance was clinically significant, if at all, and deciding upon a cut-off point would be purely arbitrary. Further research is needed to clarify this as 44% of the patient sample did not attend at least one clinic even though the vast majority would have gone on to successfully complete treatment. Poor attendance to clinic would not necessarily result in an untoward treatment outcome although there may be other negative implications both for the patient and the wider healthcare community, for example, cost of management.

In regression analysis two variables, in particular, contributed most towards variance in outcome. This inferred that patients speaking English as a first language and patients reporting negative perceptions of their illness, such as anxiety and depression, were less likely to attend scheduled clinics.

The relationship between poor attendance and English spoken as a first language does not appear to have been previously reported in similar studies. However, Story *et al.* reported in their cohort study of 1941 TB patients in Greater London that recent migrants and foreign-born individuals - those more likely to speak English as a second language - were most likely to adhere to treatment, and homeless people, problem drug users and prisoners were least likely to adhere to treatment (Story *et al.*, 2007). Therefore, in the current study, language could be a proxy measure of other social or cultural factors.

The relationship between illness perceptions and attendance was reported by Whitmarsh *et al.* in their cross-sectional study of cardiac rehabilitation (Whitmarsh *et al.*, 2003). In contrast to this study they differentiated adherers from non-adherers as being more likely to report illness consequences and distress. The differences in patient characteristics between cardiac rehabilitation and tuberculosis are considerable although this does demonstrate that the measurement of illness perceptions in relation to attendance deserves attention in relation to specific patient groups. Other studies report relationships between illness perceptions and adherence - albeit medication adherence not attendance - that are similar to the associations displayed in this study (Johnson and Folkman, 2004; Butler *et al.*, 2004; Ross *et al.*, 2004). These studies provide support for emotional perceptions explaining a component of adherence-related behaviour. However, in common with this study, all these studies are limited in their cross-sectional design such that the direction of causality cannot be assumed. For example, in the current study it is plausible that missed clinic appointments could impact negatively on emotional perceptions of illness and it cannot be assumed that patients miss-

ing clinics inherently had negative emotional representations. However, this does present a modifiable factor, whereas other variables featured in the final regression model are not modifiable. Therefore, although further research is important to confirm the relationship between emotions and adherence as well as the direction of causality, this may provide a basis on which a suitable intervention is built, such as, enhanced patient counselling centering around Cognitive Behavioural Therapy. As demonstrated in other reported studies (Petrie *et al.*, 2002), a tool such as the IPQ-R or, potentially, the new Brief IPQ (Broadbent *et al.*, 2006), could be used for screening and identifying modifiable patient behaviours that contribute negatively to patient health outcome or process.

A number of other limitations in the current study should be considered. The patient population was heterogenous and included a mix of different ethnicities and cultures as well as patients treated in three different TB services. Therefore, it is possible that recruited patients had considerably different belief systems about illness and healthcare, and that they had very different experiences within the various settings. The sample size was insufficient to specifically investigate perceptions by ethnic group and deserves further attention.

We sought, in the PUM, a tool that would succinctly measure medicines-specific perceptions in terms of their benefit and harm. However, although associations were observed between the PUM scales and other scales, this did not contribute to the final regression model. This demands the question as to whether the PUM was sufficiently sensitive to identify perceptions of harm or benefit of medicines. Alternatively, as the IPQ-R measured perceptions of treatment control it may be that this accounted for variance measured using the PUM scales. However, it is likely from analysis of responses to the various treatment-related elements of the IPQ-R and PUM that this sample of TB patients had such confidence in their treatment that the scales measured too little data variance to contribute towards the final model.

Data including patient demographics, clinical variables and patient attendance were collected from patient medical notes. There are limitations with data collected in this way not least because the investigator cannot control for accuracy. Similarly, self-reported information, such as that reported in the study questionnaire, is only as accurate as the intention of the participant to report honestly. These remain limitations of the study. Nevertheless, the authors argue that the sample size was sufficient to statistically account for random error although repeatable error, such as healthcare personnel consistently recording data inaccurately, could theoretically impact on study findings.

Finally, although the response rate (65.6%) was adequate for a study of this nature, patients who were not recruited may have altered the study findings if they had been recruited and their perceptions differed significantly from the recruited sample. It is hoped that greater exploration using the Brief-IPQ in TB Services in North East London will seek to provide a greater representation of TB patients that will serve to validate the current study findings.

**Acknowledgements**

The authors would like to acknowledge the input of Dr. D. Engova and Dr. G. Bothamley in this work.

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