

# Socio-demographic determinants of stigma among patients with pulmonary tuberculosis in Lagos, Nigeria

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## Abstract

**Background:** Patients living with tuberculosis (TB) experience significant disruption of their social life and are exposed to stigma and discrimination. This situation impacts on treatment adherence by individual patients and on disease control especially in developing nations. Different aetiological propositions have been propounded, including the relationship of tuberculosis with the Acquired Immune Deficiency Syndrome (AIDS).

**Objectives:** We sought to evaluate self-reported stigma experience among TB patients in Lagos and examine its socio-demographic determinants.

**Method:** This was a descriptive cross-sectional study, recruiting 205 patients on treatment at two government-owned referral centres for tuberculosis, using self-administered questionnaires to collect each respondent's data.

**Result:** Eighteen percent reported a previous stigma experience. Stigma experience was observed to be significantly determined by age, low socio-economic status, level of education below secondary level, disclosure of status, history of weight loss, previous smoking and alcohol history. Also, patients unable to work on clinic days were more likely to experience stigma. Sex, religion, marital status and ethnicity were not significant determinants.

**Conclusion:** Experience of stigma among patients with tuberculosis is common and may adversely affect treatment adherence. Healthcare workers and policy makers need to pay closer attention to the identified determinants for effective tuberculosis control.

**Keywords:** Tuberculosis, AIDS, stigma, disclosure, weight loss

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## Introduction

Effective control of tuberculosis (TB) has been an arduous international health challenge. The disease infects 8–10 million annually<sup>1</sup> and is currently the 7<sup>th</sup> leading cause of death worldwide<sup>2</sup>. The disease burden is greatest in Africa and Nigeria ranks fourth among twenty-two high burden countries<sup>3</sup>. TB is a chronic disease, presenting with prolonged cough and, like Acquired Immune Deficiency Syndrome (AIDS), with marked cachexia as common presenting symptoms. It leads to significant disruption of patients' life and predisposes patients to stigma and discrimination. Patients experience personal threat, social rejection and social stigma<sup>4</sup>, with women being worse hit<sup>5</sup>.

Stigma, according to Goffman, is an 'attribute that is deeply discrediting' and that reduces

the bearer from 'a whole and usual person to a tainted, discounted one'<sup>6</sup>. Link and Phelan further define stigma as existing 'when a person is identified by a label that sets the person apart and links the person to undesirable stereotypes that result in unfair treatment and discrimination'<sup>6</sup>. Different propositions have been propounded concerning the aetiology of stigma. Fear of being infected is an obvious cause of discrimination<sup>6</sup>, while scientifically unfounded beliefs about the transmission of the disease have been found to be significant predictors of stigma<sup>7</sup>. Stigma leads to discrimination, which is the 'unfair treatment of one person or group usually because of prejudice' about a specific character they possess<sup>8</sup>. Stigma and discrimination may affect the extent to which the patient is able to obtain, maintain and complete treatment<sup>9</sup>. In Ethiopia, stigma was found to be the major cause of non-compliance in the population<sup>10</sup>.

There is increased understanding of the need for emphasis on social and behavioural issues in TB

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control, for clinical success to be achieved. Most studies on this subject have assessed the common patterns of stigma among TB patients<sup>4, 6, 7</sup>, but not the determinants of this social ill. The goal of this study was to evaluate the self-reported stigma experience among TB patients in Lagos, as well as examine its socio-demographic determinants.

## Methods

The study locations were the Chest Clinics of the Lagos State University Teaching Hospital (LASUTH), Ikeja and the Mainland Hospital (formerly Infectious Disease Hospital [IDH]), Yaba. Both are referral centres for tuberculosis care in Lagos, owned by the state government. This was a descriptive cross-sectional study, conducted in July 2008, recruiting all patients who had commenced treatment for up to a week. Data collection was quantitative, with the aid of 205 pre-tested self-administered questionnaires. Nineteen questions concerning the clinical history, socio-demographic variables and patient-reported experience of stigma were employed for this study. Patients with limited literacy skills were guided.

Analysis was done using the Statistical Package for the Social Sciences (SPSS, version 12.0; SPSS Inc. 2003). The results were presented in texts and in tables. Bivariate analysis of the relationships between stigma experience and socio-demographic variables was also done using Chi square tests and significance was set at p value <0.05. Currencies are quoted in naira, conversion equivalence in US dollars at the prevailing rate at the time of the study (US\$1=N120). Ethical approval for the study was obtained from the administration of the hospitals and verbally from patients before recruitment for the study.

## Results

### Clinical and socio-demographic information

Of the 205 patients recruited, 102 were from LASUTH and 103 from IDH. The majority of the patients were male (123; 60%), with 82 females (40%). The mean age was 32.9 years ( $\pm 12.3$ ). Most patients in the study had attained secondary education or higher (81%). Above half of the study population were not married (Table 1).

In both centres, loss of weight was a very common presenting symptom among the patients (51%- LASUTH; 56%- IDH). Prolonged cough, the cardinal symptom of tuberculosis, was seen in 61% of the study population. Most patients were diagnosed with TB less than 2 months prior to the

study (Table 1). A sizeable proportion of patients (98; 48%) earned below the minimum statutory wage of ₦7500 (\$62.5) as recommended by the national government.

**Table 1: Clinical and Socio-demographic Information**

Categories	Frequency (No.)	%
Sex	Male	123 60
	Female	82 40
Age	<10 years	2 1
	11-20	22 11
	21-30	77 38
	31-40	56 27
	41-50	29 14
	51-60	12 6
	>60	7 3
Education	None	10 5
	Primary	31 15
	Secondary/ Technical	95 46
	Tertiary	69 34
Religion	Christianity	140 68
	Islam	64 31
	Traditional	1 1
Marital status	Single	110 54
	Married	84 41
	Divorced/ Widowed	11 4
	Monthly Income	₦ 7,500 or less (\$62.5 or less) 98 48
	₦ 7,501-15,000 (\$62.6 – 125) 66 32	
	₦ 15,001-50,000 (\$126 – 417) 33 16	
	₦ 50,001-100,000 (\$417 – 833) 4 2	
	Above ₦ 100,001 (Above \$834) 4 2	
Presenting complaint	Prolonged cough	125 61
	Weight loss	99 48
	Bloody sputum	5 2
	Fever, malaise, others	169 82
Time since diagnosis	< 2months	83 40
	3 -6 months	51 25
	7 – 8months	40 20
	> 8 months	31 15

### TB and social relations

About 72% of respondents [147] believed having TB had adversely affected social relationships in their daily life. Of these, TB affected relations with patients' spouses (27.5%), family (38.5%), friends (30.5%) and co-workers (27.5%) and this was not mutually exclusive. Only 81 patients [39.5%] acknowledged enjoying support from family or friends. Thirty-five percent reported reduced attendance of parties and social engagements, and 24% (49) reported significantly dwindled participation in recreation and sports.

Of the 71 patients who had a current or prior history of smoking, 42% discontinued smoking on account

of TB. Only three percent persisted despite TB infection. Eighty respondents reported a history of alcohol intake, and 41% of them discontinued on account of TB. However, 9% persisted in the intake of alcohol.

### TB and stigma

Thirty-seven patients (18%) reported a previous experience suggestive of stigma or discrimination. Stigma experience was significantly determined by disclosure of TB status to friends and colleagues. Disclosure of TB status did not significantly determine whether or not patients obtained support from family and friends (Table 2).

**Table 2: Disclosure of status and social relations**

	Categories	Disclosure of TB status		Chi-square	p-value
		Yes	no		
Stigma experience	Yes	19	18	51.457	0.000*
	No	10	158		
Support from friends and family	Yes	12	67	0.115	0.734
	No	17	109		

\*Chi square is significant

Patients presenting with history of weight loss, previous smoking or alcohol history were more likely to experience stigma. Furthermore, stigma experience was more likely among patients who did not attain secondary education or whose monthly

income was ₦ 15,000 (\$125) or less. Patients in the working age groups [20 – 50years] were more likely to experience stigma. Those unable to work due to clinic attendance were also more likely to experience stigma (Table 3).

**Table 3: Significant determinants of stigma experience among TB patients**

	Categories	Stigma experience		Chi-square	p-value
		Yes	no		
Age	Below 20yrs, above 50 yrs	3	40	4.500	<0.05
	20 – 50 yrs	34	128		
Feeling of impaired social relations	Yes	24	33	30.890	<0.001
	No	13	135		
History of weight loss	Yes	24	75	4.966	<0.05
	No	13	93		
Educational attainment	None/Primary/Technical	4	47	4.382	<0.05
	Secondary/University	33	121		
Monthly income	₦ 15000 <sup>1</sup> or less	14	74	5.339	<0.025
	Above ₦ 15000	11	11		
	Income not disclosed <sup>2</sup>	12	83		
Ability to work on clinic days	Yes	11	85	5.302	<0.025
	No	26	83		
History of smoking	Yes	29	42	38.162	<0.001
	No	8	126		
History of alcohol intake	Yes	35	45	58.592	<0.001
	No	2	123		

<sup>1</sup>₦ 15000 at the time of this study =US\$125

<sup>2</sup>Not included in the chi-square analysis

On the contrary, stigma experience was not significantly determined by patient's sex, religion, marital status or ethnic group. Stigma experience was

also not significantly determined by the centre at which the patient was receiving care (Table 4).

**Table 4: Relationships with stigma experience among TB patients that were not statistically significant**

	Categories	Stigma experience		Chi-square	p-value
		Yes	No		
Gender	Female	14	68	.088	>0.5
	Male	23	100		
Religion	Christianity	26	114	.278	>0.5
	Islam	11	53		
	Traditional	0	1		
Marital Status	Single	19	91	3.680	>0.25
	Married	17	67		
	Divorced	1	1		
	Widowed	0	9		
Tribe/ethnicity	Yoruba	20	96	4.613	>0.25
	Igbo	4	24		
	Hausa	1	5		
	North-central	1	13		
	South-south	11	28		
	North-East	0	2		
Chest Clinic Attended	LASUTH	17	85	0.262	>0.5
	IDH	20	83		

## Discussion

Stigma faced by TB patients is vague and not easily assessed<sup>11</sup>. Weight loss is a common presenting feature to TB and HIV/AIDS, making it possible for people to conflate both diseases<sup>12</sup>. Up to 48% of patients presented with weight loss in this study. This was less than the 73% obtained by Odusanya et al in their study of patients in LASUTH in 2004<sup>13</sup>. In the current study, weight loss was found to be a significant determinant of stigma experience. Studies in Thailand using focus groups among health centre staff, TB patients with or without HIV and HIV patients observed that the increased awareness of HIV/AIDS may be a cause of delays in presenting in the clinic for TB treatment.<sup>14</sup> Similar observations were made by investigators in London studying African patients.<sup>15</sup> More so, pulmonary tuberculosis is regarded by the World Health Organisation (WHO) as an AIDS-indicator condition.<sup>16</sup> This complicated relationship between HIV/AIDS and TB exposes TB patients to stigma. Further, TB patients with more severe symptoms have been reported in Thailand to have experienced greater stigma.<sup>12</sup>

Most patients understand TB through the medical model and perceive themselves as disease

vectors<sup>17</sup>. In our study, TB was observed as affecting relations with patients' spouses and their family, as well as with friends and co-workers. Many patients did not disclose their TB status, in anticipation of stigma experience, which they believed to be a corollary of disclosure. Unfortunately, most of those who disclosed were stigmatised. The London study reported actual stigma experiences to be rare, although patients felt stigmatised by the diagnosis itself<sup>15</sup>. 'External' or 'enacted' stigma is rooted mainly in fear and judgment of what is different, leading to blame, distancing, and discrimination. 'Internal stigma' - also described as felt, imagined, or self stigma - is the product of the internalization of shame, blame, hopelessness, guilt, and fear of discrimination.<sup>18</sup> One U.S. study found that internal stigma contributes significantly to levels of depression, anxiety, and hopelessness in people living with HIV<sup>18</sup>. These may lead to diagnostic and treatment delays as well as noncompliance to treatment schedule, treatment failures and, possibly, drug resistance.

Stigma experience was more common among patients in the working age groups [20 – 50years], on lower rungs of the socioeconomic ladder, with limited education and those who miss

work due to clinic attendance. In the London study, experience of TB in a known person was found to mitigate stigma.<sup>14</sup> Patients' present or previous habits, especially those with a possible social impact, like smoking and alcohol consumption also affected their stigma experience.

### Conclusion

The self-reported experience of stigma among TB patients in this study was significant. Weight loss, low socio-economic status, current or previous smoking or alcohol consumption and disclosure of TB status were identified as significant socio-demographic determinants of stigma among TB patients. Patients' work conditions may also have an impact on stigma experience.

### Recommendations

Health workers should pay closer attention to counselling patients who face the risk of stigma. The significance of disclosure should be discussed carefully with them. Local health agencies, as an extension of direct observation, may create support groups and forums for patients to share experiences. This is a practical way to mollify the stigma experience of patients, this may improve treatment adherence and contribute to disease control. Further research is required to explore the relationship between weight loss and stigma experience among tuberculosis patients.

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