Knowledge of Tuberculosis and Self Disclosure amongst Patients Accessing Treatment in an Urban Local Government Area, Lagos, South West Nigeria.

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ABSTRACT

Background: Disease-related stigma and knowledge of the disease by individual are believed to be associated with patients' willingness to seek and adhere to treatment. Increased morbidity and mortality of tuberculosis (TB) have been blamed on neglect of the human dimension of TB control. Assessing knowledge, self disclosure status and perceived stigma among TB patients would help to understand TB-related stigma as a social process and a better understanding of patients.

Methods: A descriptive cross sectional study was carried out among newly diagnosed TB patients aged ≥18 years on treatment for at least four weeks. Consecutive enrollment was carried out in all the seven DOTS centers in Ikeja LGA. Patients were asked questions about TB knowledge, self- disclosure and level of perceived stigma. Knowledge scores were grouped as poor (1-11), fair (12-17) and good (18-22). A total of 309 patients were interviewed between January and September 2012.

Results: Fifty-six percent of the patients were between 21 to 40 years with the male to female ratio of 1:1.13 while 45.3% and 51.5% had secondary school education and were married respectively. Thirty-two percent, 58% and 10% had poor, fair and good knowledge respectively. Majority (86%) of the patients have disclosed their status and treatment to family members with 39% disclosing to friends and associates. Regarding level of perceived stigma, 50% reported that having TB is an embarrassment to the family while 77% and 68% reported that TB patients should not share plates and sleep on the same bed with others respectively. Those with good knowledge and those that have retired from active service were more likely to self-disclose to family members than others (p<0.05).

Conclusion: Although perceived stigma and poor knowledge of TB was common among patients, most still disclosed status to family members. Health education of new patients on TB should be intensified.

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INTRODUCTION

Tuberculosis (TB) is a chronic, infectious disease caused by bacteria, *Mycobacterium tuberculosis*. Almost every organ in the body can be affected, but involvement of the lungs (pulmonary TB) accounts for more than 80% ofthecases. TB is transmitted by droplets in the air produced when an infected person coughs, spits or sneezes, and inhaled by surrounding people.[1]

TB is a leading cause of adult death in the world, killing 1.7 million people each year. Globally, 14.6 million people have active TB disease: each year 8.9 million people develop active TB, the impact of TB is such that in 1993 it was declared to be a global emergency by the World Health Organization (WHO).[2] Nigeria ranks fourth among the 22 high burden countries for TB in the world. It is estimated that about 290/100,000 population (365,400) of tuberculosis cases occur annually in Nigeria, of which 50% are smear-positive.[2]TB control in Nigeria is based on the WHO Strategy- Directly Observed Treatment Short course (DOTS). This means that TB patient swallows the tablets under the supervision of a health worker or designated community member. Such treatment lasts for 6 months and requires regular visits to a health center; daily for the first two months; and then monthly thereafter.[1] These visits to health centers and the symptoms of TB (chronic cough, weight loss and weakness) make it difficult for TB patients to disguise the fact that they have the disease. Once identified, patients experience considerable stigma and discrimination on account of their disease, leading to delays in diagnosis and treatment, adversely affecting the TB control effort.[3] Stigma related to chronic health conditions such as HIV/AIDS and

tuberculosis is a global phenomenon with severe impact on individuals and their families, and on the effectiveness of public health programs.[3]

People with TB suffer from discrimination and stigma, rejection and social isolation. These result in depression, anxiety and low level of life satisfaction further adding to the burden of the TB.[4] There are lots of misconceptions surrounding TB treatment. Some people believe that people die when they go on TB treatment so they don't come forward for treatment while others believe TB treatment has side effects like change in skin colour and hair texture so everyone knows one has TB.[5]

Stigma has been defined as a social reaction which spoils normal identity and could mean: disapproval, condemning, symbol of disgrace.[6] It has also been defined as 'existing stigma' 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.[7]

A sense of desperation and fear of judgmental approach from health workers may lead to inappropriate health seeking behavior that may further increase the tuberculosis burden. A study carried out in Nepal among TB patients identified self-stigmatization on transmission of TB and perceptions that TB was a divine punishment. Furthermore, some patients felt they were discriminated against by health workers.[7] Studies have shown that analyzing tuberculosis-related social stigma as a social process enables one to better understand some key social structural factors of health care system's organization and identify locally acceptable interventions to reduce such stigma.[6]

This study therefore sought to assess the knowledge of tuberculosis among patient receiving treatment, self-disclosure of their status to either family or friends and their level of perceived stigma. This would serve as a baseline for the provision of vital information, education and communication which would serve to reduce the stigma associated with TB and thus promote early diagnosis and treatment, better adherence to drug therapy, increased effectiveness of TB control and therefore a reduction in the disease burden.

METHODOLOGY

Study area: Ikeja local government area is one of the 16 urban LGA in Lagos State. There are seven DOTS centers in the LGA. These centers are managed by the Directorate of Disease control of the Lagos State Ministry of Health. TB care is delivered through national TB and leprosy control program and this ensures the availability and quality of free sputum examination in government health laboratories and free TB treatment provided exclusively in these centers. In each health center, a nurse or community health officer is usually responsible for the TB patients care.

Study population: The study population includes all adults aged ≥18 years that were diagnosed with active TB disease according to national TB program guidelines, registered for TB treatment at any of the seven facilities offering DOTs services in Ikeja LGA

Study design: A descriptive cross-sectional study was carried out among adults aged ≥18 years that were diagnosed with active TB disease and have received anti TB therapy for at least four weeks before enrollment into the study.

Study duration: The total duration of the study was nine months, January to September 2012.

Sample size calculation: Minimum sample size for the study was determined using the formula:[8]

$N = (Z)^2 pq / d^2$, where n= minimum sample size, Z= normal standard deviate to the desired confidence level of 95 % for this study (1.96), p= prevalence, q = 1-p, (A study done in rural Edo State, Nigeria reported 55% TB knowledge.)[9] Substituting these values, a minimum sample size of 380 was required. However, applying the formula for finite population correction factor where N is < 100,000, [Nf =n/ (1+n/N)] gave a minimum of 201 because an average of 350 patients is seen yearly in Ikeja LGA where the study was conducted.

Sampling technique: A total of 309 patients were recruited for the study. The patients were recruited

proportionally according to the volume of patients seen at participating DOTS centers with the teaching hospital contributing about two–thirds of the patients.

Data collection: The study instrument was a pretested structured questionnaire containing both closed and open ended questions. The instrument was divided into three sections, (i) socio-demographic characteristics, (ii) respondents' knowledge of TB aetiology and treatment and (iii) disclosure status and perceived stigma questions. The questionnaires were administered to clients at the end of their visit by trained research assistants (community health extension workers).

All TB patients, including persons that had relapsed and those that returned after default, were included. Pregnant women were excluded, because their care involved multiple providers. Patients who consented to enrollment into the study were physically examined and the study instrument administered. For this study, patients received the usual care for TB.

Data analysis: The completed questionnaires were entered into computer; data edited and necessary correction carried out before entry. There were 22 questions with regards to patients' knowledge of TB (aetiology and treatment). Patients were scored as poor (1-11), fair (12-17) and good (18-22). Perceived stigma was measured using three parameters and a positive (Yes) response in all the three parameters was considered as stigma. Results were presented in frequency distributions of all relevant variable, means and standard deviations calculated while test of significance using chi-square, t-test and Yates correction were conducted using Epi-Info 6.1 software package and the significant level was set at 5%.

Ethical consideration: Approval for the study was obtained from the Lagos State University Teaching Hospital Health Research and Ethics Committee. Informed verbal consent was obtained from participants at the time of data collection. Confidentiality and use of data for research purposes was maintained throughout the study.

RESULTS

A total of 309 patients were recruited comprising 164 males and 145 females. The age of the patients ranged between 15-77 years with mean $\pm$ SD of 36 $\pm$ 12.9 years. About two-thirds (56%) were in the age group 21-40 years. Thirty three (11%) and 69 (22%) of the patients smoked cigarette and took alcohol respectively. About a quarter (29%) of the patients had municipal water supply with the most frequent type of accommodation being one room, 104 (34%) and self-contained flat, 80 (26%). (Table I)

Majority of the patients (284, 92%) had pulmonary TB with about one tenth (25, 8%) having extra pulmonary TB. Thirty seven (12%) of the patients were co infect with HIV, however, about a quarter (22.3%) did not know their status. Majority of the patients sought medical care first at government hospital (211, 68%), 92 (30%) of the patients were first seen at a private hospital while 2% of the patients first sought treatment in either a spiritual home or from a traditional healer. (Table I)

About two thirds (58%) of the patients had fair knowledge of the aetiology, clinical features and treatment of tuberculosis. The knowledge score ranged from one to twenty out of a possible maximum score of 22 with the mean$\pm$ sd score of 13$\pm$3.7 (Table II)

More than four fifth of the patients have disclosed their TB status and treatment to their family members, with only 39% disclosing to their friends and associates. With regards to level of perceived stigma, about three quarters (77%), more than two thirds (68%), and half (50%) of the patients reported that patients with TB should not share plates, should not sleep on the same bed with others and having TB is an embarrassment to their family respectively.

Age and employment status were statistically significantly associated with self-disclosure, p<0.05. Those who were retired were more likely to self-disclose to family members. Patients' knowledge about tuberculosis was also statistically significantly associated with their self-disclosure; those with better knowledge were more likely to self-disclose their status and treatment to both family and close friends.

Table I : Socio-demographic characteristics and clinical status of patients

Characteristic	Frequency (N=309)	Percentage (%)
Age (Years)		
<21	33	10.7
21 - 30	87	28.2
31 - 40	87	28.2
41 - 50	52	16.8
51 - 60	36	11.7
>60	14	4.5
Gender		
Female	145	46.9
Male	164	53.1
Formal Education		
None	7	2.3
Primary	41	13.3
Secondary	140	45.3
Tertiary	121	39.2
Marital Status		
Single	122	39.5
Married	159	51.5
Divorced/Separated	26	8.4
Widowed	2	0.6
Employment Status		
Employed	103	33.3
Self-employed	105	34.0
Unemployed	82	26.5
Retired	19	6.1
Religion		
Christianity	203	65.7
Islam	106	34.3
Type of Accommodation		
One room	104	33.7
A Room and Parlour	58	18.8
Self-Contained Flat	67	21.7
Others (specify)	80	25.9
Source of Drinking Water		
Well	12	3.9
Borehole	118	38.2
Tap water	86	27.8
Others	93	30.1
Cigarette Smoking		
Yes	33	10.7
No	276	89.3
TB disease classification		
Pulmonary	284	91.9
Extra Pulmonary	25	8.1
HIV Status		
Positive	37	210
Negative	203	65.7
Don't know	69	22.3
First point of Care		
Government hospital	211	68.3
Private hospital	92	29.8
Traditional healer	1	0.3
Spiritual home	5	1.6

Table II: Knowledge Grade of patients concerning tuberculosis

Knowledge Score*	Frequency (N=309)	Percentage (%)
Poor (1-11)	99	32.0
Fair (12-17)	178	57.6
Good (18-22)	32	10.4

* Maximum obtainable score was 22.

Table III: Socio-demographic characteristics of patients and self-disclosure of tuberculosis to family members

Characteristics	Self-disclosure to family N (%)			Test of Significance
	Yes	No	Total	
Age group				
<21	31	2 (6.1%)	35 (100%)	X2= 12.076
21 -30	(93.9%)	10 (11.5%)	87 (100%)	df = 5
31-40	77 (88.5%)	19 (21.8%)	87 (100%)	p = 0.034
41-50	68 (78.2%)	3 (5.8%)	52 (100%)	
51-60	49 (94.2%)	5 (13.9%)	36 (100%)	
>60	31 (86.1%)	4 (28.6%)	14 (100%)	
	10 (71.4%)			
Gender				X2= 0.864
Female	122 (84.1%)	23 (15.9%)	145 (100%)	df = 1
Male	144 (87.8%)	20 (12.2%)	164 (100%)	p = 0.353
Formal education				
None	6 (85.7%)	1 (14.3%)	7 (100%)	X2= 1.387
Primary	34 (82.9%)	7 (17.1%)	41 (100%)	df = 3
Secondary	124 (88.6%)	16 (11.4%)	120 (100%)	p = 0.708
Tertiary	102 (84.3%)	19 (15.7%)	121 (100%)	
Marital status				
Single	104 (85.2%)	18 (14.8%)	122 (100%)	X2= 8.558
Married	142 (89.3%)	17 (10.7%)	159 (100%)	df = 4
Divorced	9 (64.3%)	5 (35.7%)	14 (100%)	p = 0.073
Separated	9 (75.0%)	3 (25.0%)	12 (100%)	
Widowed	2 (100.0%)	0 (.0%)	2 (100%)	
Employment status				
Employed	83 (80.6%)	20 (19.4%)	103 (100%)	X2 = 10.461
Self-employed	97 (92.4%)	8 (7.6%)	105 (100%)	df = 3
Unemployed	67 (81.7%)	15 (18.3%)	82 (100%)	p = 0.015
Retired	19 (100.0%)	0 (0.0%)	19 (100%)	
Religion				X2= 0.367
Christianity	173 (85.2%)	30 (14.8%)	203 (100%)	df = 1
Islam	93 (87.7%)	13 (12.3%)	106 (100%)	p = 0.544

Table IV: Patients' knowledge and their perception of stigma and self-disclosure of tuberculosis

Knowledge grade	Perceived stigma N (%)			Test of significance
	Yes	No	Total	
Poor	39 (39.4%)	60 (60.6%)	99 (100%)	X^2= 6.360
Fair	95 (53.4%)	83 (46.6%)	178 (100%)	df = 2
Good	19 (59.4%)	13 (40.6%)	32 (100%)	p = 0.042

Knowledge grade	Self-disclosure to family N (%)			Test of Significance
	Yes	No	Total	
Poor	83 (83.8%)	16 (16.2%)	99 (100%)	X2= 0.995
Fair	154 (86.5%)	24 (13.5%)	178 (100%)	df = 2
Good	29 (90.6%)	3 (9.4%)	32 (100%)	p = 0.608

Knowledge grade	Self-disclosure to friends and close associates N (%)			Test of significance
	Yes	No	Total	
Poor	30 (30.3%)	69 (69.7%)	99 (100%)	X2= 7.211
Fair	71 (39.9%)	107 (60.1%)	178 (100%)	df = 2
Good	18 (56.3%)	14 (43.8%)	32 (100%)	p = 0.027

DISCUSSION

This study set out to determine the knowledge, level of self-disclosure of tuberculosis status and treatment (to either family members or close friends), and level of perceived stigma. The majority

of patients who participated in the study were between 21 and 40 years. This population is in agreement with other studies.[10]

Correct knowledge and positive perception of the patients towards TB, and its management is a major factor in the success of TB control programme in any TB burden countries. In this study, 58% of the patients had fair knowledge of the aetiology, clinical features and treatment of tuberculosis. About a third (32%) of the patients had poor knowledge of tuberculosis; this is in keeping with findings from several studies.[11,12] A low knowledge of tuberculosis is a likely cause of the delay in seeking treatment and has also been linked to stigma and the social consequences of TB.[13] This study also aimed to understand to whom TB patients disclose their diagnoses, such information may enhance our understanding of the social experiences of TB patients following their diagnosis, and may also inform treatment programs. Majority of the patients (86%) disclosed their status and treatment to other family members while 33.8% reported to have disclosed their status to close friends. This is not surprising as one will feel more comfortable to discuss such stigmatizing condition to close relatives rather than friends.

This finding corroborates what was observed in Malawi, where tuberculosis patients went ahead to disclose their diagnosis to significant others who they felt comfortable with despite feeling that they might be stigmatized against.[10]

Another finding of great significance from this study is that patients who had a better knowledge of tuberculosis were more likely to self-disclose their condition to both family and close friends. This is important in health education interventions. Disclosure has great implications for the management of tuberculosis in terms of support for accessing and adhering to treatment.[15] Disclosure is equally important for helping to reduce the spread of infection to others.[16] Thus it is assumed that disclosure may improve patient outcomes although this study did not explore such associations.

Studies have reported that TB patients isolated themselves from friends and family, not only because of a fear of infecting others, but because of fear of discrimination.[7] The high level of perceived stigma (77%) reported in this study is therefore not surprising. However, despite this high level of perceived stigma, the patients still disclosed their status to family members. This may be connected to the realization that they will need substantial social support for the proper management of tuberculosis.[7] This assumption is further strengthened from the finding that patients who were retired were more likely to self-disclose their condition to their family members.

CONCLUSION

The finding of the study showed that there is poor knowledge of tuberculosis among the study population. However, despite the high level of perceived stigma most of them still disclosed their status to family members. Efforts to improve and strengthen health education in tuberculosis clinics especially newly diagnosed patient is recommended as this will reduce stigma and the impact of social consequences of TB. In addition, further research is needed to investigate the relationship between self-disclosure and patient outcomes.

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