Knowledge, attitudes and beliefs about tuberculosis in urban Morocco

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المعارف والمواقف والمعتقدات المحيطة بمرض السل في المناطق الحضرية في المغرب صلاح الدين العثماني، زياد اوبرماير، نعيمة بنشيخ، جواد المحجور

الخلاصة: استهدف الدار سون تحديد المفاهيم المتعلقة بمرض السل بين السكان الحضريين في المغرب. ولذا فقد أجري مسح شمل 301 شخصاً، كان منهم من هو خاضع للمعالجة من مرض السل (مرضى)، والبعض ممن يُراجع المرافق الصحية لأسباب مرضية أخرى (ليسوا بمرضى سل)، وذلك في مدينتين من مدن المغرب. ولم يستطع معظم المرضى تحديد مرضهم على أنه سل، بل أشاروا إليه على أنه عرض بدني. وجنّح غير المرضى إلى إرجاع العوامل السببية إلى الظروف المعيشية، والأحوال المنزلية والعائلة. ولقد اتضح أن هنالك وصمة ترافق مع الإصابة بمرض السل. وكان الغالبية من غير المرضى على علم بإمكانية المعالجة من السل، وقليل منهم كان يعلم بإمكانية الحصول على الخدمات التشخيصية والعلاجية مجاناً. أما إدراك العامَّة حول مسببات السل وسبل انتقاله فقد تفاوتت من الناحية الطبية البيولوجية، مما يُبرز الحاجة إلى تحسين الإعلام والتواصل حول هذا المرض.

ARSTRACT We sought to characterize conceptions of tuberculosis (TB) in an urban population in Morocco. Thus 301 subjects, some being treated for TB (patients) and some attending health facilities for other conditions (non-patients), in 2 Moroccan cities were surveyed. Most patients did not identify their illness as TB referring instead to a body region or symptom. Non-patients tended to cite causative factors related to living conditions, home and family. There was considerable stigma associated with TB. Most non-patients knew that TB was treatable, but few were aware that diagnosis and treatment were free. Popular understandings of TB etiology and transmission in this population differ from the biomedical view, highlighting the need for better communication about the disease.

Connaissances, attitudes et croyances relatives à la tuberculose en milieu urbain au Maroc

RÉSUMÉ Nous avons cherché à décrire la façon dont est perçue la tuberculose dans une population urbaine au Maroc. Notre étude a porté sur 301 sujets qui, pour certains, recevaient un traitement antituberculeux (patients) et pour d'autres, se rendaient dans des établissements de santé pour d'autres maladies (non-patients), dans deux villes marocaines. La plupart des patients ne mettaient pas le nom de « tuberculose » sur leur maladie, mais évoquaient plutôt une région du corps ou un symptôme. Les non-patients avaient tendance à évoquer des facteurs causals liés aux conditions de vie, au logement et à la famille. La tuberculose suscitait énormément de préjugés défavorables. La plupart des non-patients savaient que la tuberculose pouvait se soigner, mais beaucoup ignoraient que le diagnostic et le traitement étaient gratuits. Les idées sur l'étiologie et la transmission de la tuberculose qui circulaient dans cette population s'opposent au point de vue biomédical, ce qui met en lumière la nécessité d'une meilleure communication sur cette maladie.

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298

Introduction

Morocco has had a national tuberculosis control programme for more than 40 years, and was one of the first countries to adopt the DOTS (directly observed treatment, short-course) strategy in the early 1990s. For the past 10 years, the Moroccan National Tuberculosis Programme (NTP) is estimated to have met and exceeded international targets for estimated case detection and treatment success rates [*1*]. The NTP is fully funded by the Moroccan government, providing consultation and treatment at no cost to patients.

The Moroccan NTP uses passive casefinding, a method of case detection that relies on patients to present themselves to public health facilities for diagnosis and treatment. It is thus important to understand the factors that encourage and discourage patients to seek care. Knowledge and perceptions of illness and its treatment are known to affect the way in which tuberculosis patients utilize health services [2-6]. This study sought to examine beliefs surrounding tuberculosis in Morocco, in both tuberculosis patients and others seeking care in public health facilities, with a view to understanding care-seeking behaviour. Specific factors explored were the nature of tuberculosis and its transmission; the stigma attached to the illness and its consequences; and patients' understandings of health service provision for tuberculosis.

Methods

The study population was drawn from 2 urban regions of Morocco thought to have high rates of tuberculosis: the prefecture of Ben M'sik-Sidi Othman in the city of Casablanca and the prefectures of Fes-Medina and Zouagha-Moulay Yacoub in the city of Fes. In both cities, 3 government community health centres were selected, along with 1 government health centre specializing in management of tuberculosis and chest diseases. These centres were chosen because they serve the mostly urban, poor patient groups that are of primary interest to the tuberculosis control programme, and because personnel at these centres had the training and ability to carry out the survey.

The population was selected to represent 3 distinct populations of adults (over 20 years old): 1) patients diagnosed with tuberculosis and currently undergoing treatment; 2) patients who were suspected of having tuberculosis but had not yet undergone confirmation by appropriate investigation, including sputum testing; and 3) a group of patients meant to represent the general population, who presented to the same health centres for illnesses unrelated to tuberculosis. The latter 2 were grouped into the category of non-patients, and results from these 2 groups are presented together unless noted otherwise.

The survey was designed to elicit subjects' views about 3 main topics: the nature of tuberculosis and its transmission, stigma surrounding the disease, and knowledge of treatment and health service provision. Specific questions on these topics were tailored to individual patient groups. Tuberculosis patients were administered an open questionnaire, aimed at understanding how they viewed their own illness, instances of stigmatization they had faced, and knowledge of available health services including treatment. Non-patients were given a modified closed questionnaire administered by an interviewer, designed to explore popular notions of tuberculosis etiology and transmission, the perceived stigma attached to the disease, awareness of services offered. and sources of information about tuberculosis.

La Revue de Santé de la Méditerranée orientale, Vol. 14, Nº 2, 2008

The questionnaire was first field tested in the city of Rabat, then applied to the sites of this study. In both Casablanca and Fes, the team consisted of 1 supervisor and 2 researchers recruited from the health personnel of the facilities. Researchers were given a training session on quantitative and qualitative research methods. Patients entering the study facilities during the study period (summer 2000) (4 days in each city) were enrolled in the study serially until the quotas for each patient group were reached (60 subjects for patients and suspected cases, 180 for other health service users), with informed consent obtained in line with national standards. Results were aggregated and analysed by the study team in Microsoft Excel. The study was designed in conformity with the ethical standards of the Moroccan NTP and Ministry of Health.

Results

Sociodemographic characteristics of the study sample are summarized in Table 1. The respondents were was mostly urban residents with little or no education. Just over half (52%) were unemployed. Fifty-six per cent (56%) of the subjects had been referred to the public tuberculosis health services by a private doctor. Of the patients under treatment for tuberculosis, 13% had undergone treatment for over 6 months, implying a continuation, relapse or chronic case.

Knowledge of tuberculosis

Patients being treated for tuberculosis had a variety of different answers when asked to describe the nature of their illness (Table 2). Only 1 in 5 patients responded that he/ she was suffering from tuberculosis (*sall*). The commonest answer was a reference to the affected body region, namely the chest

Table 1 Population characteristics		
Characteristic	No.	%
Reason for visit		
Known tuberculosisª	61	20
Suspected tuberculosis	60	20
Other	180	60
Location		
Casablanca	151	50
Fes	150	50
Milieu		
Urban	290	96
Rural⁵	11	4
Age (years)		
20–24	72	24
25–34	94	32
35–44	76	25
45+	59	20
Sex		
Male	141	47
Female	160	53
Education		
None	138	46
Primary	82	27
Secondary	81	27
Employment		
Unemployed	158	52
Unskilled/semi-skilled	61	20
Professional/student	74	25
Other	8	3
Total	301	100

^aOne additional patient was recruited to ensure that the sample size of 60 would be reached if any questionnaires proved unusable.

^bAlthough the study was conducted in an urban setting, some patients were rural residents temporarily in town.

(*sdar*). Others cited more traditional understandings of excess water (*mayy*) in the abdomen. Still others identified their problem in terms of symptoms experienced.

Only 9% of non-patients identified an infectious cause when asked about the etiology of tuberculosis. The majority of these instead had conceptions of tuberculosis

300

Eastern Mediterranean Health Journal, Vol. 14, No. 2, 2008

Table 2 Tuberculosis	patients'	description of
their own illness		

Description	No. (<i>n</i> = 61)	%
Chest (as-sdar)	25	41
Tuberculosis (<i>as-sall</i>)	12	20
Water inside stomach (al-mayy fi dloue/ fil-karch)	4	7
Lymph node (<i>al-oualssis</i>)	4	7
Cough (<i>al-koha</i>)	2	3
Hot/cold sensations (as-sakhana/al-bard)	2	3
Lungs (<i>arriya</i>)	1	2
Other/unknown	11	18

divergent from the strict biomedical view, ranging from environmental to hereditary (Table 3). Asked to elaborate on specific ways that tuberculosis was transmitted, most non-patients referred to causes related to the home or interpersonal relations (Table 4). In view of the discrepancies between patients' views and biomedical theory, it is interesting to consider the ways in which patients learn about tuberculosis. Of patients who had been referred to tuberculosis clinics for suspected active tuberculosis, 85% indicated that they had not received

Table 3	3 Cause	of tuberculosis	according	to
non-pa	atients			

Cause cited ^a	No. (<i>n</i> = 240)	%
Living conditions	42	18
Economic situation	29	12
Food/nutrition	29	12
Hereditary/family conditions	23	10
Infection	22	9
Psychological	5	2
Other/unknown	90	37
and the answer was possible		

^aOnly 1 answer was possible.

Table 4 Mode of transmission of tuberculosisaccording to non-patients		
Mode of transmission ^a	No. (<i>n</i> = 240)	%
Domestic objects	201	84
Sexual relations	168	82
Food/nutrition	192	80
Saliva	188	78
Personal objects	177	74
Blood	170	71
Living conditions	157	65
Work/school	151	63
Air	139	58
Street/public place	127	53

^aMultiple answers were possible.

any information about tuberculosis from the health services. For patients consulting for reasons other than tuberculosis, the main sources of information about tuberculosis were the media (radio, television and newspapers: 43%) and word of mouth (friends, family, "the street": 42%).

Stigma

We found evidence of significant stigma against patients with tuberculosis. A significant number of tuberculosis patients had experienced instances of discrimination or prejudice, the results of which are summarized in Table 5. Only 27% of non-patients considered the larger community to be accepting of tuberculosis patients and 32% believed that it was appropriate to avoid a patient with tuberculosis. The stigma of tuberculosis seemed to affect women in specific ways; in the sample of non-patients, 54% believed that a woman with tuberculosis should not marry and 18% believed that a woman who contracts tuberculosis should be divorced by her husband.

Such wariness of tuberculosis extends to medical settings. Of the tuberculosis patients, 72% believed that they should be La Revue de Santé de la Méditerranée orientale, Vol. 14, Nº 2, 2008

Table 5 Negative consequences of tuberculosis according to patients

Consequence ^a	No. (<i>n</i> = 61)	%
Loss of work	11	18
Abandonment by friends	3	5
Loss of housing	2	3
Divorce	2	3
Abandonment by family	2	3
Stopping studies	1	2
Total⁵	21	34

^aMultiple answers not accepted.

^bThe remaining study participants reported no negative consequences

isolated from other patients in hospital; a further 46% also believed that they should be isolated from other tuberculosis patients. Of the non-patients, 75% believed that they could contract tuberculosis from entering a clinic with infected patients.

Treatment and utilization of health services

Patients were asked how long they had delayed in seeking care from the onset of symptoms, and how they managed their treatment regimen. In this population, the mean delay from the onset of symptoms until presenting to a health professional was 49 days, with 40% of patients delaying for 1 month or more. Although almost all the patients (98%) reported being committed to finishing their treatment, only 38% were aware of approximately how much longer their treatment would last under the standard 6-month DOTS regimen.

Non-patients' level of knowledge about the availability of treatment was also assessed. Seventy-one per cent (71%) of the non-patients believed that tuberculosis was fully curable, and 85% were aware that specific services existed for the treatment of tuberculosis within the health system. However, only 40% of the non-patients were aware that services for tuberculosis patients were offered free of charge.

Discussion

This study sought to document knowledge and beliefs surrounding tuberculosis in Morocco. The population sampled was generally urban and poor, with levels of education and employment lower than the general population as measured by the DHS Morocco 2003–2004 survey [7]. These patients are likely to be representative of the population where tuberculosis is most prevalent.

Beliefs about the nature and transmission of tuberculosis among respondents diverged from biomedical knowledge. One of the most surprising results was that most tuberculosis patients did not conceive of their illness in terms of a specific microbiological diagnosis. More often, they framed their response in terms of a body region or a key symptom. This suggests that patients did not think that their disease was caused by a foreign organism, but rather was a property of their own bodies. The majority of non-patients likewise did not identify tuberculosis as an infectious disease, but saw it as resulting from living conditions, socioeconomic factors, food, behavioural factors and family background. Notions of disease transmission were similarly grounded in everyday life - bodily fluids, household contacts and food.

This "endogenous" conception of tuberculosis may be linked to the stigmatization described in this study: the disease was seen to arise from the personal and family lives of patients, not from a random airborne infection. The stigmatization that women in particular suffered may reflect this same perceived link between tuberculosis and home and family life. Health care workers often report that patients expressed fear Eastern Mediterranean Health Journal, Vol. 14, No. 2, 2008

that women in particular might contaminate their family members, especially children living in their household (Chentoufi A. Personal communication, 2004).

Interestingly, despite lack of awareness of infection as the proximal cause of tuberculosis, respondents' views of causation corresponded in some degree with known risk factors for infection. The 4 factors most commonly cited as "causes" of tuberculosis are known risk factors for infection: living conditions, socioeconomic status, nutrition [8,9], and having a family member with tuberculosis [10,11]. Thus popular beliefs in this instance corresponded to empirical knowledge of the distal causes of tuberculosis.

Our study suggests clues regarding the factors that contribute to diagnostic delay, the time during which patients with active pulmonary tuberculosis transmit the disease. These include lack of knowledge about the disease, stigma, not knowing that free treatment is available, and fear of exposure to contagion in the tuberculosis clinic. These are comparable to factors highlighted by studies in other settings [3, 12-14].

This study is limited by the relatively small sample size and the different tools that were used in the different sites, which precludes formal statistical analyses. The results do, however, describe prevalent views of the disease and provide indications regarding the connections between these beliefs and patterns of health service utilization. Building on previous studies [15, 16], there is an opportunity to focus education about tuberculosis using patients' beliefs as a starting point.

Conclusions

Most patients in this predominantly urban sample had little knowledge of tuberculosis, its causes, or its transmission. The popular conception of tuberculosis that emerged from this study was that of a disease with its roots in the social and personal lives of its victims. Such beliefs may contribute to the under-utilization of health services as well as the significant stigma of tuberculosis in Morocco. There is an opportunity for health services to work with patients and the general population, starting from their own beliefs, to help them gain a better understanding of the disease and its treatment. which may lead to more treatment and less stigma.

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304