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Patients' experience with tuberculosis and healthcare in sub-Saharan Africa

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Perceptions, health care seeking behaviour and the implementation of a tuberculosis control programme in Lambaréné, Gabon

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ABSTRACT

Setting: Lambaréné, Gabon.

Objectives: To describe patients' perceptions of tuberculosis (TB) and to determine factors that influence their health care seeking behaviour in order to gain insight in the management of TB.

Design: Participant observation, in-depth semi-structured interviews and focus group discussions were conducted with 30 TB patients, 36 relatives, 11 health care providers and 18 traditional and spiritual healers. Recruitment of patients was linked to the PanEpi study and took place at the Albert Schweitzer Hospital, the General Hospital and the human immunodeficiency virus (HIV)-TB clinic.

Results: Patients generally described TB as a natural and/or magical disease. The majority of the patients combined treatment at the hospital with (herbal) self-treatment, traditional, and spiritual healing. Despite the free availability of TB treatment in principle, patient adherence was problematic, hindering effective TB control. Most patients delayed or abandoned TB treatment due to financial constraints, stigmatisation, ignorance about treatment, change of health care service, or use of non-prescribed antibiotics. The situation was occasionally complicated by drug stock-outs.

Conclusion: There is an urgent need to bridge the gap between patients and the hospital by avoiding drug shortages, intensifying cultural-sensitive TB health education, embedding TB care into the cultural context and enhancing cooperation between hospitals, patients, traditional healers and communities.

With an estimated worldwide incidence of 9.4 million cases in 2009, tuberculosis (TB) remains a major public health problem and the epidemic is increasing, despite efforts to contain it.¹ Eighty per cent of all TB patients live in sub-Saharan Africa,² where the disease is putting enormous pressure on many health care systems.

In Gabon, the estimated incidence of TB is 450 per 100 000 population: 46% of all TB patients are co-infected with human immunodeficiency virus (HIV), and 10% have multi-drug resistant (MDR)-TB³ posing a severe Global Public Health threat. The Gabonese National TB programme (NTP) is responsible for (passive) case detection and provides antituberculous treatment without cost, however stock-outs occur repeatedly, there is no countrywide infrastructure for sputum culture and drug susceptibility testing, and the World Health Organization (WHO) promoted TB control strategy is not implemented. As in other settings,⁴⁻⁷ adherence and compliance problems contribute to a low (34%) TB treatment completion rate, with 45% patients abandoning treatment.⁸

In general, cultural, economic, and social considerations play a significant role in treatment adherence. Traditional and spiritual healing services, which are commonly used by Gabonese TB patients, constitute an important alternative to hospital services. Economic factors are significant as TB, classified as disease of the poor and facilitated by inadequate nutrition or overcrowded living conditions, places a financial burden on most patients.^{6,7,9} Gabonese patients often face financial problems regarding transport or in accessing treatment during the frequent temporary national drug stock-outs. Social constraints exist as TB often generates stigma, a discrediting social label.^{7,10,11}

In Gabon, little research has been conducted so far on TB.^{8,12,13} No medical socio-anthropological TB research has been published, whilst previously published studies from other areas have proven important for health care improvement.^{4-7,11} Considering the major issues surrounding TB in Gabon, such research is highly relevant as it provides knowledge about the health care seeking behaviour of patients, which may guide the development of interventions for the prevention and control of TB.

METHODS

The study population consisted of patients (aged >18 and diagnosed with TB) recruited into an ongoing TB epidemiology study in Lambaréné, Gabon. Families of patients, health care providers, traditional healers registered with the Gabonese National Traditional Healer Association, and spiritual healers (Catholic, Protestant, Pentecostal, Celeste, and Reveil churches) were approached. In 2012, a four-month case study was conducted using a mixed-methods approach that consisted of document analysis, participant observation, in-depth

semi-structured interviews, and focus group discussions. Participant observation was conducted at the Albert Schweitzer Hospital, the general regional hospital, the governmental ambulatory health care centre for HIV and TB, patients' homes, traditional healing sessions, spiritual healing sessions, and l'Institut de Pharmacopée et de Médecine Traditionnelles (governmental institute for herbal treatment). Respondents were interviewed repeatedly using a questionnaire on socio-demographics, treatment, perceptions about TB, health care services, and stigma. The latter three topics were also discussed during two focus group discussions with TB patients, acquaintances, and health care providers. Ethical approval was obtained from the institutional review board of the Centre de Recherches Médicales de Lambaréné (CEI-MRU number: 011/2012). Informed consent was provided by respondents before recruitment, interviews, and observation.

RESULTS

Thirty TB patients, 36 relatives, 11 health care providers, and 18 traditional/spiritual healers were included. Patients attended the hospital to see a doctor and for sputum analysis after a period of coughing and/or being ill [range two weeks - two years] and were generally unaware of having TB (27/30, 90%). At arrival, the majority of the patients (18/30, 60%) had already developed signs and symptoms that had profoundly compromised their activities of daily living. Almost half of the patients (14/30, 47%) were so ill that they were convinced they would not survive. Four patients (13%) died due to TB during the four-month study period. Eight patients (27%) abandoned the treatment provided by the hospital.

Perceptions of tuberculosis

An examination of local terms for TB revealed five aetiological principles: 1) *vampires* or *fusils nocturnes* (night rifles), i.e. evil spirits launched with sorcery, 2) *poisons*, 3) *demons*, Gabonese nature spirit, 4) *germs*, and 5) *God*. TB caused by the first three principles was called *magical TB* (*disease from the Blacks*) in contrast to the latter two principles which caused *natural TB* (*disease from the Whites*). Sometimes TB was considered both magical and natural referring to at least two of the aetiological principles. Twenty-four patients (80%) believed evil spirits could make you ill. The remaining six patients and all of the spiritual healers acknowledged the existence of spirits, but said not to believe in them, as this could aggravate illness.

Respondents described different ways of diagnosing the cause of TB. Although hospital tests were seen as the best method, only seven patients (23%) initially made use of these. Positive test results were explained as patients having natural TB, while negative results suggested magical origins. However, sometimes

diagnostic difficulties (sputum negative or extra-pulmonary TB) or inadequate diagnostics (e.g. only taking a blood sample) could at times be interpreted as magical TB (interviews with health care providers, focus group discussions). Moreover, if TB was diagnosed magically by spiritual or traditional healers, the patients did not attend the hospital, believing that the *Treatment from the Whites* would not be effective.

Anti-tuberculosis treatment

Twenty-two patients (73%) agreed that magical TB could only be treated by a traditional or spiritual healer, in contrast to natural TB, which could additionally be cured in the hospital. Six patients (20%) reported TB did not have magical causes and thought that it could only be cured in the hospital.

The majority of the patients had turned to various forms of health care, such as (medicinal) plants, pharmacy, *fokoro* (antibiotics without prescription), the hospital, traditional healing, and spiritual healing (prayer or exorcism) (Table 1). Twenty-two patients (73%) combined western and spiritual or traditional health care, mostly successively (20/30, 67) when TB perceptions changed or different healing services were viewed as effective yet too powerful to be used simultaneously.

Table 1 Health care services for TB patients in Gabon

Patients' Choice for Health Care Service				
Nr.	First	Second	Third	Fourth
1	Plants	Traditional healer	Hospital	
2	Plants	Hospital	Traditional healer	
3	Plants	Exorcism & prayer	Fokoro	Hospital
4	Plants	Exorcism & prayer	Fokoro	Hospital
5	Plants	Traditional healer	Hospital & prayer	
6	Plants	Hospital		
7	Plants	Exorcism & prayer	Hospital	
8	Plants	Hospital		
9	Plants	Hospital & prayer		
10	Plants	Pharmacy	4 traditional healers	Hospital
11	Plants	Pharmacy	Hospital & prayer	Traditional healer*
12	Plants	Traditional healer	Hospital	
13	Plants & traditional healer	Hospital	Traditional healer	
14	Plants & Fokoro	Hospital & prayer		
15	Plants & pharmacy	Hospital & prayer	Exorcism	

Table 1 Health care services for TB patients in Gabon

Patients' Choice for Health Care Service				
Nr.	First	Second	Third	Fourth
16	Hospital			
17	Hospital			
18	Hospital & prayer			
19	Hospital & prayer			
20	Hospital	Traditional healer		
21	Hospital & exorcism & prayer			
22	Hospital & plants	Traditional healer**		
23	Pharmacy	Plants	Hospital	
24	Pharmacy	Hospital		
25	Pharmacy	Traditional healer	Hospital	
26	Pharmacy	Hospital & traditional healer		
27	Pharmacy	Hospital & prayer	Traditional healer*	
28	Pharmacy	Hospital		
29	Pharmacy & prayer	Hospital		
30	Fokoro	Hospital & prayer		

* Option for the future, in case hospital treatment would not work

** Patient died before going to traditional healer

Fifteen patients (50%) initially used (medicinal) plants. All respondents said that in almost every Gabonese family someone had traditional knowledge about herbal treatments, making this healing method common and easily accessible.

'When I fell ill, my mother started of course with the trick of the village. She used wood, leaves, medication to get me back, to get me better.'

(Patient interview)

One third of the patients (9/30, 30%) first went to the pharmacy or bought fokoro, believing their TB to be an ordinary fever or cough. A third group began with a hospital visit (7/30, 23%).

For many of the patients, the hospital was not the first choice of health care, and even considered problematic or unacceptable by some. Long treatment and correct use of anti-tuberculosis medication were difficult since they explained that *'many Gabonese patients have "another concept of time", being less punctual or future-oriented'* (interviews with health care providers, participant observation). Moreover, many Gabonese people did not believe that diseases could be chronic or prolonged; rather diseases were considered as instantly

curable. Some patients felt that the Whites and their hospitals were a threat to traditional health care services (interviews with health care providers, three patients, focus group discussions, participant observation).

Almost a quarter of the respondents (7/30, 23%) explained the importance of traditional health care, which is deeply anchored in local religion. Use of traditional health care requires an initiation ritual, a ceremony to become part of the ethnic group, as illustrated by the following quote:

'I was initiated. That is obligatory here in the village. You have to secure yourself against sorcery and vampires. I was 12 and wanted my initiation so badly. All my friends had done it already.'

(Patient interview)

Informants explained that without initiation there was a risk of becoming marginalised: *'Because you are not protected against evil spirits and more important, you are not part of the group'* (Patient interview).

Almost half of the patients made use of spiritual healing, through prayer (13/30, 43%) and exorcism (4/30, 13%). According to these patients and spiritual healers, this gave strong (psychological) support. Two patients and two spiritual healers described how certain spiritual healers prevented patients from going to the hospital as they claimed this was unnecessary.

Socio-economic factors

Most patients (28/30, 93%) had a low socio-economic status, as determined from their housing, education, and stories (interviews, participant observation). They lived in wooden houses with few windows and no running water. Patients lived with on average six other household members [range 0-30]. Nineteen patients (63%) were financially responsible for their family, their disease therefore placed a significant economic burden on the household. Two patients (7%) had postponed a hospital visit, because they were unable to leave work for financial reasons or children, or pay for transport.

In principle, the NTP covered anti-tuberculosis medications, but patients occasionally had to buy their drugs from local pharmacies (maximum €70-110 per month) due to drug shortages, resulting in three patients (9%) abandoning treatment. Traditional healers charged around €200 for treating TB, which was sometimes cheaper and more accessible being located in the villages.

Generally, the educational level of patients was low; they (had) attended primary school (67%) secondary school (37%), or an occupational training courses (9%). None of the patients nor their families knew in advance that anti-tuberculosis treatment was provided free of charge. Health care providers, two spiritual healers, and three traditional healers were aware of this. Two patients (7%) abandoned treatment, because they felt cured, not realising that they could

relapse. TB was only briefly discussed in primary school. One non-governmental organisation for TB was located in Libreville, but no campaigns had been conducted in Lambaréné.

The majority of the patients felt stigmatised describing their disease as socially problematic (20/30, 67%). They understood people's fear of becoming infected and therefore occasionally concealed from others the fact that they had TB (Table 2). Two patients (7%) denied having TB and three patients (9%) had an acquaintance who denied having TB. Going to a traditional healer guaranteed greater privacy, as they were located nearby and visits could be arranged quickly. As a consequence some patients felt less stigmatised (focus group discussions, participant observation, interviews patients & health care providers).

Table 2 Stigma and TB patients in Gabon

Experience with stigma	Number (percentage)	
Not problematic	10/30	(33%)
Not (or less) problematic, because TB is curable	15/30	(50%)
Problematic	20/30	(67%)
Difficulties at social level	17/30	(57%)
Trouble at work	2/30	(7%)
Only informing some people about their TB	8/30	(27%)
Hiding/refusing their TB	2/30	(7%)
Knowing someone who hides/refuses TB	3/30	(10%)
Double stigma: TB & HIV	4/30	(13%)
No TB stigma, only HIV stigma	2/30	(7%)

DISCUSSION

In Gabon, TB remains a major issue despite the free access to anti-tuberculosis drugs. Based on an analysis of TB perceptions and the health care seeking behaviour of TB patients, this case study demonstrates how cultural, social and economic factors influencing patient adherence prevent successful implementation of the TB control programme.

Illness perceptions are an important focus of medical research as these generally affect health care seeking behaviour.¹⁴⁻¹⁹ In Gabon, the respondents explained TB in a biomedical (*natural*) or a traditional or religious (*magical*) way. This dichotomy is often described in African settings,^{11,16,20,21} having *natural* TB explained *how* a patient got infected with TB bacteria, but did not explain *why* the person got ill. Having *magical* TB meant jealous people had performed sorcery on the patient. In contrast to a Tanzanian study on malaria,²¹ traditional explanations were used not only when medical knowledge met its limits, such

as in the case of negative test results or treatment failure: inadequate diagnostics additionally evoked at times suspicions of magical TB, which called for traditional or spiritual healing. Moreover, when traditional or spiritual healers diagnosed *magical* TB, patients were encouraged to avoid the hospital or to abandon treatment as the *Treatment from the Whites* was considered ineffective.

It thus becomes clear why patient and care giver perceptions of TB are an essential factor in health care seeking behaviour. There may have been a selection bias in the study, as all patients were recruited from recognised health care services. Nevertheless, valuable insights were gained, as most respondents did not present first to the hospital, a finding that is in contrast with a Kenyan study⁷. Data were gathered regarding patients' *pluralistic health treatment*,^{4,11,19,22,23} i.e. combining various formal and informal health care services, such as hospitals, pharmacies, traditional or spiritual healers, and herbal treatment.

Hospital delays and treatment abandonment led in approximately half of the cases to such a poor state of health that the patients were convinced that they would not survive. This was related to patients' poor financial situation or the patients' impression of being healthy, a finding supported by previous work on TB in Gabon.⁸ However, drug shortages, the availability of *fokoro*, usage of alternative health care services, and stigma were other important determinants. As previous research suggests, the degree of TB-related stigma was not as great as HIV-related stigma,¹¹ yet TB-HIV co-infected patients were often double stigmatised. Felt or feared stigma occasionally led to fear of disclosure and self-exclusion from health care services.²⁵ One study described how the chronic nature of TB aggravated stigma.⁷ Interestingly, during focus group discussions and interviews, TB stigma was often denied because of the curable nature of the disease. In fact, it was said that many Gabonese people denied the concept of chronic or long-term diseases, and preferred traditional healers, who supposedly provided immediate cure.

Structural factors, such as poverty, poor infrastructure, or NTP drug shortages negatively impacted the patient's ability to adhere to treatment. The majority of the TB patients had a low socio-economic status and faced financial difficulties with transport or drugs. In Gabon, the distance to the health centre is the most important determinant of survival for malaria patients.^{20,26,27} Traditional healing was occasionally considered by patients to be cheaper and more convenient, in line with reports from other studies.^{6,7} However, traditional healing sessions were also oftentimes expensive. Furthermore, none of the patients knew that anti-tuberculosis medication at the hospital was provided free of charge in principle.

TB is an under-addressed topic in Gabonese health education and the early symptoms are often initially believed to be an ordinary cough, hence a preference for herbal treatment. People should be made more aware of TB symptoms and the danger of prolonged self-treatment. In addition, an understanding of adequate anti-tuberculosis treatment is necessary to avoid the development

of drug resistance. Furthermore, the consequences of fokoro use should be researched in Gabon, where the prevalence of MDR-TB among TB cases is 10%³ and a second-line drug repository is lacking,¹³ this is highly urgent.

The usual theories on poverty and low level of education do not adequately explain the spread of TB however. Important too, especially in rural areas, were deep-seated traditional beliefs and the fear of being marginalised if TB patients did not use traditional healing. Protection against witchcraft and magical diseases provided by a traditional healer was often socially mandatory. However, these social expectations and associated power structures have not been reported by previous socio-anthropological TB studies.^{5,6,11,25} This finding highlights the need for culturally sensitive TB health education in which traditional and religious perceptions and practices are not neglected, but identified as part of the cultural context. Similarly, embedding the medical perspective into the socio-cultural context could advance communication between health care providers and patients.^{6,7,25}

Interaction between hospitals and traditional and spiritual healers is advocated by the WHO.²⁸ In the light of the fact that that 30% of the TB patients presented to traditional healers, such calls for integration of traditional healers into national health systems should receive continued support. This collaboration is important to soften patients' defensive attitude to hospitals and encourage patient adherence.

Previous work has elaborated on the substantial influence of family and community members on health care seeking behaviour resulting in shorter hospital delay⁶. Their influence and possible cooperation should be further explored.

CONCLUSION

Attention should be given to the influence of structural, cultural, and socio-economic factors on the health care seeking behaviour of TB patients, as this has a major impact on infection and the emergence of MDR-TB. In addition to structural improvements in hospital diagnostics, availability of drugs, and reduction of transport costs, it is important to provide culturally sensitive TB education, embed medical perspectives into the cultural context, and involve traditional and spiritual healers and communities in bridging the gap between patients and caregivers to improve TB control.

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