

From their own perspective. A Kenyan community's perception of tuberculosis

R. Liefoghe,¹ J. B. Baliddawa², E. M. Kipruto³, C. Vermeire² and A. O. De Munyck¹

¹ Department of Clinical Sciences, Unit of Epidemiology, Institute of Tropical Medicine, Antwerpen, Belgium

² Faculty of Health Sciences, Moi University, Eldoret, Kenya

³ School for Social, Cultural and Development Studies, Moi University, Eldoret, Kenya

Summary

Early passive case finding and treatment compliance are the cornerstones of tuberculosis (TB) control programs. As human behaviour plays a critical role in both strategies, a better understanding of it is important for the planning and implementation of a successful TB programme, especially for the health education component. Our qualitative study in Uasin Gishu, Kenya, aimed at a better understanding of the community's beliefs and perceptions of TB, recognition of early symptoms and health-seeking behaviour. Five focus groups with a total of 49 people were held: one with hospitalised TB patients, two with rural and two with urban participants.

Tuberculosis is well known in the communities and many vernacular names for the disease exist. TB is perceived as a contagious, 'sensitive' disease difficult to diagnose and treat. Community members believe that TB should be diagnosed and treated in a hospital or by a medical doctor and not at the peripheric level. TB treatment is perceived as long, agonising and cumbersome. Traditional treatment is considered a valid alternative to modern treatment, believed to be as effective and much shorter. Initial symptoms such as cough and fever are often overlooked and/or confused with malaria or a common cold. Symptoms associated with the disease refer to the later stage of TB. TB is attributed to causes such as smoking, alcohol, hard work, exposure to cold and sharing with TB patients. Many participants believe TB is hereditary. Prolonged self-treatment and consultation with the traditional health sector as well as the social stigma attached to the disease increase patient's delay. Only after symptoms persist for some time and/or the suspect's health deteriorates, are modern health services consulted. These social conditions necessitate culturally sensitive health education, taking into account local perceptions of TB.

keywords tuberculosis, knowledge, perception, health-seeking behaviour, patient's delay, Kenya.

correspondence R. Liefoghe, Department of Clinical Sciences, Unit of Epidemiology, Institute of Tropical Medicine, Nationalestraat 155, 2000 Antwerpen, Belgium

Introduction

The magnitude and importance of the problem of tuberculosis (TB), especially in developing countries, is well documented (Murray *et al.* 1990; Kochi 1991; Sudre *et al.* 1992; Nunn & Enarson 1994) and a top priority for action. Early passive case detection and treatment compliance are the pillars of success in TB control

programs. Passive case detection relies on self-presentation to a health worker by persons with symptoms indicative of TB. To achieve good control, adequate resources and health infrastructures, including a functional bacteriological network capable of investigating all TB suspects, are essential prerequisites (Fox 1988). They may not always be sufficient because human behaviour is also a critical element. There is

R. Liefoghe *et al.* **A Kenyan community's perception of TB**

increasing recognition of the need to have a better understanding of the role of the behavioural factors in TB control (Rubel & Garro 1992; Barnhoorn & Adriaanse 1992; Sumartojo 1993; CDC 1995; Liefoghe *et al.* 1995).

The relationship between culture, health-related beliefs and health behaviour is complex. Personal experiences, attitudes of the social network and health beliefs interact and influence health-seeking behaviour. Several authors agree that the human element in TB control has often been overlooked (Rubel & Garro 1992; Grange & Festenstein 1993; Westaway & Wolmarans 1994). According to Rubel & Garro (1992), TB control could improve significantly if more consideration were given to the health culture of the population. Local surveys on knowledge and attitudes towards TB are of great benefit in the planning and implementation of control programs, particularly their health education element (Grange & Festenstein 1993). A recent CDC Workshop on TB and behaviour highlighted the necessity of improving public knowledge on TB prevention and treatment: Health education should be directed at both individuals and communities and should not only impart knowledge, but also address the myths surrounding TB (Johnson & Heitzer-Allen 1995). Health education interventions often failed in the past. Some critics concluded that promoting behavioural changes obscures underlying structural and political problems and is tantamount to victim-blaming (Thomas 1990). Research from the last decade shows health promotion interventions have failed because they were designed without knowledge of the health behaviour of the target population (Godin & Shepard 1983; Godin 1989). Methods such as personal interviews or focus group discussions are indicated to assess the knowledge and attitudes regarding TB (Johnson & Heitzer-Allen 1995). Such a focus group discussion in Sialkot, Pakistan (Liefoghe *et al.* 1995) highlighted the need to provide culturally sensitive health education, counselling of patients and relatives and the necessity to change the attitudes of medical and paramedical staff.

Study aims

We used the focus group method to gain more insight into the beliefs and attitudes surrounding TB in the Uasin Gishu District Hospital catchment area, Kenya.

Our study sought to understand the community's beliefs and knowledge about the causation, transmission and symptomatology of tuberculosis; to determine treatment-seeking behavioural patterns in tuberculosis suspects; and to assess attitudes towards the disease and the afflicted patients. Our findings should enable the regional TB authorities to design and implement a health education campaign relevant to the perception of tuberculosis in the community.

Material and methods**Study area**

The study was conducted in the Uasin Gishu District Hospital catchment area in 1994. Uasin Gishu District is situated in the north-western region of Kenya and covers 3784 km²; its relatively stable but ethnically diverse population of 508102 inhabitants is composed mainly of individuals from different Kenyan tribes. The main commercial and administrative centre is Eldoret town with a population of about 200 000. The district's health facilities comprise Eldoret District Hospital, 3 private hospitals, 12 health centres and 24 dispensaries providing curative and preventive health care. Eldoret District Hospital has a 72-bed medical ward and a 17-bed TB ward.

The boundaries of the district hospital's catchment area do not fully coincide with the district boundaries and some nearby health centres in neighbouring Nandi district also belong to the Uasin Gishu District Hospital catchment area. In this paper the Uasin Gishu District Hospital catchment area is simply referred to as Uasin Gishu.

TB is a major health problem in Kenya. The reported case detection for all forms of tuberculosis reached 57 per 100 000 in 1991. Since then, case detection rates have increased by 20% for all forms of TB and by 10% for smear-positive cases, which is partly explained by the rising HIV/AIDS epidemic. In 1993, 20451 TB cases were reported by the National Leprosy and Tuberculosis Programme (NLTP), not counting an unknown number detected and treated in private institutions (Ministry of Health 1993). Kenya has a well-functioning National Tuberculosis Programme with clearly defined norms and strategies (NLTP 1993). Its policy is to integrate TB control in the Primary Health Care Strategy. The majority of TB patients, mainly pulmonary, are seen by

R. Liefvooghe *et al.* **A Kenyan community's perception of TB**

a clinical officer specially trained in TB and Leprosy management.

The current upward trend in the annual number of new TB cases has also been observed in the Uasin Gishu area. The reported incidence of sputum-positive cases increased from 124 in 1992 to 1997 in 1993. In governmental health care facilities, the diagnosis of TB is made on the basis of sputum smear examinations and chest X-ray. While until 1995 TB treatment was based on the 1STH/11TH drug regimen, now the 8-month short course therapy is being introduced. Active contact tracing and primary prophylaxis are not routinely provided for in the district. From TB registers and case records it appears that the defaulter rate for sputum-positive patients is about 35%; the reasons for this high rate remain unclear.

Method

We used the focus group discussion method. A focus group discussion (FGD) is a qualitative research method increasingly advocated in medical research (Palm & Windahl 1988; Khan & Manderson 1992; Dawson *et al.* 1993). Focus group discussions are informal sessions in which participants are asked to discuss their perceptions on a specific topic. The discussions are specifically designed to yield information on the community's beliefs, values and understanding of health problems (Bash 1987; Ezeh 1993; Jaffre & Prual 1994), and permit rapid ethnographic assessment of barriers to health behaviour (Coreil *et al.* 1989).

We chose the FGD method because it allows a more in-depth discussion of the topics than social surveys by standardized questionnaires; it also has the benefit of group synergy. Compared to in-depth interviews, group interaction stimulates richer responses as it allows participants to agree or disagree (Feyisetan 1994). Discussions can also generate more critical comments than interviews (Kitzinger 1995). Questioning is flexible in FGD, and it may be easier to reveal participants' real perceptions: 'FGDs reach the parts that other methods can not reach' (Kitzinger 1994). As an example, all female rural participants first acknowledged that a sick person would always consult a doctor and it was only after some discussion that they spontaneously brought up the role of traditional healers.

A question guide was developed (Appendix 1 and 2) and translated into the local vernacular Nandi and into

Swahili, the two commonly used languages in the area. The focus group discussions were conducted by trained moderators and recorded on audio-cassettes. These were then transcribed and translated. The content was analysed with Textbase Alpha by three independent social scientists: two from Moi University, Kenya and one from the Institute of Tropical Medicine, Belgium.

Five focus groups were formed, four from the communities and one consisting of hospitalized TB patients. As few TB patients were hospitalised during the study period, this FGD was limited to 8 male participants. Since rural and urban communities have different educational and social backgrounds, two rural and two urban community groups were formed. To avoid male dominance in the groups, discussions for women and men were conducted in separate groups. On average each group consisted of 10 participants (range 8–13) selected by convenience sampling: those persons who could provide the best information for the discussions and who were willing to participate. They had been contacted through the local chiefs. Freely given informed consent was obtained from all participants. The 5 focus group discussion sessions were conducted over a period of 8 weeks. Each group met only once.

The rural community members were from Mosoriot, a small shopping centre in Mutwot, Nandi District. The location falls within Uasin Gishu District Hospital catchment area. Two groups were formed: one consisted of 13 men and another of 11 women. The men's mean age was 37.6 years (SD 11.0) years; the women's, 30.2 years (SD 5.0). Most men were small farmers, some traders and others skilled labourers, while the majority of the women were housewives. As may be expected, some rural participants knew each other. Although conventionally the FGD methodology advocates the recruitment of strangers, this has recently been recognized as an unnecessary and overly rigid restriction (Morgan & Kreuger 1993).

The urban participants consisted of 9 males and 8 females, all residents of Eldoret town. Less than half were natives of the area, the rest came from different provinces within Kenya. Except for 4 university students and 2 housewives, the urban participants were professionals. The mean age for males was 34.2 years (SD 5.9) years, for females, 26.4 years (SD 4.8).

The TB patients came from different parts of Uasin Gishu District, with an average age of 28.9 (SD 9.7) years. Most were small-scale farmers. All patients were

sputum-positive pulmonary TB cases at the initial stage of the mandatory hospitalization period. Given the ethnical variation of the population, all focus groups consisted of participants from different Kenyan tribes.

Results

General perceptions and beliefs

The FGD with the community members was introduced as follows: 'Someone I know told me he has TB. What do you know about this disease?' Apparently TB was widely known among the participants and many spontaneously reported that they had observed a TB case in their near surroundings. TB was perceived as a dangerous disease that affects the lungs, chest or air passage. It was seen as 'sensitive' because it is considered to be highly contagious. Contact with people who have contracted TB is avoided and people themselves take preventive measures to limit the danger of infection. TB was also labelled as a 'dangerous disease' because it is difficult to cure. Despite the availability of 'a large quantity of drugs, both traditional healers and doctors may be defeated by the disease and the affected person often ends up dying.' It requires hospitalization and long duration of drug intake to be cured. TB was also perceived as 'a difficult disease' because it disrupts patients' social life, leading to social isolation and stigmatization not just for the patient, but for the family too. Tuberculosis places socio-economic constraints on the sufferer in that he or she is unable to work, placing an additional financial burden on the patient and family members. Especially participants from the urban community associated TB with a particular class and group of people in the society, namely the 'low class kind of society, the poor'.

Local terms

From the focus group discussions it was clear that every ethnic community involved had a vernacular name or at least a descriptive reference for the disease. Although the FGD did not cover all ethnic groups and dialects, the findings illustrate that many communities in the country know that the disease exists and that it mainly affects the lungs. An overview of the names that emerged from the discussions are presented in Table 1. The local terms reflect that TB is perceived as a chronic disease which affects the lungs and may result in the death of the

affected person. It is interesting to note that there was an extensive argument among the rural women as to whether TB was called *chebuonit* or *kipkokondet*. They eventually agreed that *chebuonit* refers to TB while *kipkokondet* denotes asthma. *Kifua kikuu*, the Kiswahili name, emerged in most discussion groups.

Recognition of early signs and symptoms

Continuous, persistent and prolonged cough was the symptom of tuberculosis most frequently mentioned by all groups. The cough is accompanied by other symptoms such as difficulties in breathing, wheezing and chest pains. Loss of appetite and consequent weight loss are also considered typical symptoms. TB sufferers become very thin and weak. They are tired, lack energy and are no longer able to work. In all groups participants recognized 'coughing blood' as a definite sign of tuberculosis. Sputum and high temperature were less often cited but some participants said that 'feeling cold' is a typical sign. Other symptoms mentioned were vomiting, constipation and sleeping difficulties due to coughing.

Several participants from the rural communities remarked that TB patients' 'facial looks change, the colour of the skin becomes darker and even the texture of the skin changes'. Other rural participants also pointed out that TB patients show food preferences (cold food) and do not eat all kinds of foods (hot food). Recognition of the signs and symptoms was summarized by one of the rural participants as follows:

If that is the case, it can be seen from his cough and the look of his body. He becomes weak, can't do any work and any slight drop of temperature and he will look for fire. He can't also walk far. A person will first sit around weakly. He changes colour. If he was light he becomes darker. He starts to lose weight and fears to take a cold bath. If we see all these, we can say that one has tuberculosis.

The TB patients explained which symptoms and signs prompted them to seek medical attention. Only one stated that it was prolonged cough with production of sputum. All patients reported that their persistent cough initially did not worry them. For the majority, sharp chest pain, breathing difficulties, vomiting blood, loss of appetite or 'feeling very tired' were the symptoms that made them consult health services. High fever and night

Table 1 Local terms for TB

Term for TB	Ethnic Community	Meaning
<i>chebuonit</i>	Kalenji Rift Valley Province.	'Disease based in the lungs and the lungs can swell until they can finish the person'
<i>kiploleit</i>	Kalenji Rift Valley.	'Coughing or continuous cough'
<i>kahera</i>	Luo Nyanza province	'That cough that never clears. A disease that never disappears. It can be in the chest.'
<i>olwera</i>	Luhya Western Province	'A disease that usually affects the lungs and chest'
<i>sifo ba syangarasha</i>	Bukusu (Luhya) Western Province.	'A kind of disease where one keeps coughing for a long time or you can even end up dying'
<i>obulwai ba sirifu</i>	Banyala (Luhya) Western Province	'Disease associated with the chest ... problems with breathing system, the results being thin, coughing and...death.'
At present TB, before <i>murimu</i> was used	Kikuyu Central Province	'Refers to the consequences of isolation, ... you could not greet somebody with your hand when you had this disease'.
<i>itirian</i>	Turkana Northern part Rift Valley.	'Coughing without stopping, ... until you do not have space for breathing and even sleeping'
<i>kifua kikuu</i>	Kiswahili National language	'Extraordinary ailment of the chest'.

sweats caused 3 patients to confuse their condition with malaria. For all patients the symptoms they mentioned had persisted for a long time. The difficulties of early recognition of the symptoms were summarized by one of the patients who stated that 'the disease takes a long time for its symptoms to be seen'. Tuberculosis was seen as a disease easily confused with asthma, pneumonia, and cancer. Both rural and urban participants pointed out that it was difficult to distinguish TB from Aids as both diseases present similar symptoms

The relation between these diseases is that a person starts losing weight and then his skin starts drying up.

Transmission and causes of tuberculosis

Lifestyle and eating habits of the victim came up as significant causes of TB, coupled with drinking of 'traditional' alcohol and cigarette smoking. Familial inheritance also featured strongly among a number of participants. There is a common belief that inheritance and familial association constitute a mechanism of transmitting TB. There were discordant ideas as to whether this was because of genetic inheritance or merely due to the close proximity among the family members. This belief seemed to hold likewise among the

TB patients. Bewitching and cursing were also mentioned.

One other deep-seated belief of all participants was that sharing of facilities with infected persons will surely cause tuberculosis. Sharing rooms, utensils, beds and bedding, food and drinks, talking with infected persons contribute greatly to the spread of the disease. Participants specifically pointed out careless spitting as an important transmission mechanism. Both community members and patients mentioned instructions given by health professionals, especially to TB patients and their relatives, as the source of this information.

Urban participants, especially the women, seemed better informed than the rest. Most knew that TB is infectious and can be contracted by inhaling contaminated air. This was seen as the most important cause of TB in small children. Some urban participants suggested that TB is a waterborne disease; others linked the cause to a person's immunity and socio-economic status by saying that persons

with strong blood are likely to be more resistant than those with weak blood

implying that some people are more predisposed to TB infection than others. Some urban participants were

aware of the relation between TB and HIV. While half of the TB patients had previously had close contact with TB patients, none had considered the possibility of being infected. They blamed exposure to cold, hard work and smoking as the causes of their ailment.

Health-seeking behaviour

Community members were asked to describe where a person with symptoms of TB would seek help for his/her ailment. The answers were not merely hypothetical as many participants were able to relate what they had observed in the case of a family member, a friend or neighbour. The patients, of course, put forward their own experience. Figure 1 illustrates the health-seeking behaviour (HSB) patterns that emerged. Usually treatment steps were sequential but in some instances simultaneous resort was mentioned. Whenever a person felt any form of illness or discomfort, self-treatment was initiated. This was done by using herbs, drugs from the shops or left-over drugs from friends and relatives. They would also take drugs advertised by the media. The rural community would tend to start self-treatment with traditional medicine, then move to self-treatment with modern drugs before consulting modern health services. TB patients went to modern health services once they experienced general discomfort and pain.

Community members considered modern medicine especially indicated for purposes of diagnosis, initiation of treatment, second opinion of diagnosis or for medical reviews. They discussed at length as to where it was preferable to consult first, but no clear consensus was obtained. Some mentioned dispensaries, others clinics, while some still felt that it was better to consult the hospital directly. It was clearly stated, especially by the rural community, that modern health services at the

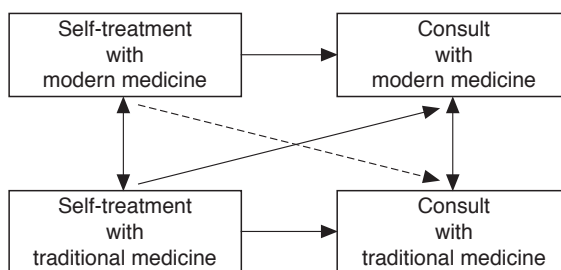


Figure 1 Patterns of health seeking behaviour of TB suspects in Uasin Gishu, Kenya.

rural level were not adequately equipped and lacked doctors to diagnose TB satisfactorily. Because TB is perceived as a 'sensitive' disease, hospitals were seen as the best places for diagnosis and specialized, expert care. Traditional healers were consulted at some stage of the illness. Urban and rural community members, especially the rural women, felt that traditional healers should not be overlooked. They thought that after getting diagnosed at the hospital, there is nothing wrong with receiving treatment from the traditional healers and they saw traditional healers' medications as less cumbersome than modern treatment. Others reinforced the idea that the two services could be used side by side. Some felt that traditional health care was better than modern services. The use of traditional healers was seen as a valid alternative when the modern health services had failed or when there was no improvement in the patient's condition. Traditional healers were considered easily accessible and have the added advantage that they are often paid after the patient has been cured.

Delay in receiving appropriate TB treatment

All TB patients reported a delay of several months, sometimes a year or more, between onset of the symptoms and initiation of TB treatment. For several TB patients appropriate treatment was delayed because they believed that they were suffering from something other than tuberculosis. Prolonged self-medication also delayed correct treatment. Only after symptoms persisted for a period of time patients felt the need to seek medical attention.

A few patients mentioned that they were incorrectly diagnosed at their first place of consultation (dispensary, health centre or hospital), which caused further delay. Female community members felt that the delay was due to patients concealing their health status for fear of isolation, which was mentioned as another inhibiting factor. The long treatment was also seen as an interference in the daily life of the family.

Decision to seek medical attention

The initial decision to seek medical attention came from various sources. The family was considered to be influential in this decision, through finding the money for treatment and assisting in identifying suitable health

R. Liefvooghe *et al.* **A Kenyan community's perception of TB**

facilities. The term 'family' was used collectively to refer to family members without distinguishing/pinpointing a particular person. Other persons instrumental in helping the patient decide to seek medical attention were friends, neighbours, community leaders, community members and health workers. Teachers were also mentioned as giving advice to their students to seek medical attention on noticing such signs as persistent coughing. One patient actually confirmed that he was assisted by the school to seek medical attention. Urban participants pointed out the mass media influence through instructions such as 'should symptoms persist seek medical advice'.

Curability

Community participants were asked whether they believed that TB could be cured, and mixed responses were recorded. Many thought that it can be cured but not completely. Most rural participants had this idea 'because one might only feel better after this disease'. It was claimed that a TB patient might never be the same again. Few participants, however, were convinced that TB was completely curable. Those who thought it was curable, felt this was only possible if the patient complies strictly with the doctor's instructions. Several participants from the urban community noted that cure could only be achieved if TB is diagnosed early and proper treatment promptly started. One participant agreed with the early treatment but emphasized that traditional medicine could actually cure the disease at its late stage. Pessimism about curability exists because despite all the medicine and personnel available, combating the disease remains an arduous task. As one participant put it

even the (medical) doctor can be defeated and likewise a medicine man.

The question of curability was a very sensitive one for the TB patients. They all expressed their belief that those who comply with the doctor's instructions will be cured, though they seemed uncomfortable discussing this subject further. One TB patient phrased his doubts about the curability of TB:

Because this disease establishes itself well in a person and you see when something gets well established in you it will be very hard to destroy it, therefore to get rid of this disease in us is hard.

Treatment

TB treatment is perceived by the community as: '... rough, agonising and even devastating for the patient'. This was expressed by a participant of the urban community:

Look, hospital treatment will treat you according to the injections. In the hospital you are given 130 injections. Once you have gone through this course, you will never go back to the hospital again.

Opinions on adequate length of TB treatment varied between 3 months and 2–3 years. Some rural men even mentioned a treatment of 2–3 years with hospitalization of up to 3 months, while for noncompliant patients, it could take up to 10 years. The underlying belief, however, was that if the disease is diagnosed early enough, treatment will take a shorter time and cure is possible. It was apparent that 'treatment' and 'curability' were often considered synonymously in the focus group discussion. In general, community members felt that the effectiveness of traditional healing was underestimated, and one of the participants said that 'he had seen it takes no more than 2 months'.

Community's attitudes towards tuberculosis patients

The community's perception of TB strongly influences the attitudes towards TB patients. As TB is known as 'a very serious disease because it is very contagious', community members will avoid contact with TB patients and as a result the patient and her/his family will be isolated. Sometimes relatives even stop children from having contact with their parents who have TB. Children are instructed how to avoid contact with TB patients. Utensils are kept separately and often it is suggested that the patient should take meals separately and live in separate quarters.

So what also happens is, when you come to someone suffering from TB, it's likely that he will be within the confines of his family. You will find such people are not welcomed where people are. You will be advised against going with other people's children or visiting freely to stay in other people's home. I will also say there is that tendency of people to restrict movement. You are given a special residence.

Some community members are aware that this

R. Liefoghe *et al.* **A Kenyan community's perception of TB**

isolation must be psychologically very difficult for the patient. Patients try to hide their disease but still need the support from their surroundings. Isolation is enhanced by the uncertainty surrounding the curability of TB: even after patients have fully recovered they may be avoided because

They always may suffer from the disease again.

By the nature of TB, I mean it is a sensitive disease ... Because it can be transmitted ... a person does not want to share it out to a very close person because it is a very disturbing disease. And yet he does not want everybody to know.

The TB patients confirmed that their environment reacted negatively: 'friends keep off ... when they meet outside they will not even greet you.' Relatives were shocked when the diagnosis was disclosed and feared that they might also be infected. Nevertheless all patients confirmed that their close relatives were very supportive and assisted them in finding funds for their treatment. Several community participants stated that the concept of isolation originates from the way TB patients are treated in hospital. TB patients are isolated in TB wards; few visitors are allowed and it is believed that special measures are taken to avoid contamination, such as doormats being impregnated with chemicals, or putting on gloves before entering the TB ward.

Discussion

Perception, beliefs and knowledge about the causation, transmission and symptomatology of tuberculosis

The community's perception of tuberculosis includes what they understand about the disease and their explanatory model. The latter refers to signs and symptoms by which the illness is recognized, presumed causes of the illness, recommended treatments, pathophysiology of the illness and prognosis (Kleinman 1980a). Local explanatory models may differ from biomedical ones and may define the care patients seek for. In Uasin Gishu TB is perceived as a dangerous, chronic, infectious lung disease difficult to treat and often fatal. In many other parts of the world TB is still perceived as a disease to be feared. Kleinman (1980b) found in Taiwan that TB, together with leprosy and mental illness, was considered as very dangerous and the most shameful of diseases.

The local names given to tuberculosis reflect how people perceive the disease. Most local names describe TB as a chronic disease that affects the lungs, and often a reference to the fatal end is included. Other traditional names emphasize the concept of losing weight or becoming thin. The names given to TB describe the disease in its later, and often fatal, stage. These findings agree with research from Nepal, where the traditional name for TB is *kapate*, a term which describes a broken clay cooking pot. Smith (1994a) states that 'the analogy is clear and parallels the old expression of phthisis and consumption; TB is a wasting and debilitating disease'. Understanding the local terms is important because they indicate the symptoms most people associate with the disease. On asking the people in Uasin Gishu what signs and symptoms they associate with TB, prolonged and persistent cough was the most frequently mentioned sign but almost always combined with other symptoms. Haemoptysis is seen as a typical symptom of TB. Both the local names and the description of signs and symptoms point to the suspicion of TB in its later stage. This conclusion is reinforced by the TB patients' account: while all TB patients were coughing, none, except one, sought appropriate treatment unless the cough was accompanied by other severe symptoms. Similar findings are reported from Hong Kong (Allan *et al.* 1979), where only 15% of the patients sought treatment solely due to a cough, while in Nepal (Smith 1994b) weight loss, not coughing, is associated with TB.

Symptoms in the early stage of the disease are not very specific and often confounded with common infections like a cold or malaria, and only if symptoms become worse or persist will the suspect consult a health service. In a study among Mexican workers Rubel & Garro (1992) also found that most of the TB patients attributed their symptoms to benign conditions such as flu or bronchitis.

Beliefs concerning the cause of the disease are important determinants of health-seeking behaviour. In Uasin Gishu District smoking and alcohol feature prominently, and many people believe that TB is inherited. The hereditary nature of TB was widely accepted in the past in the Western world (Comstock 1994). We found that similar beliefs are prevalent in other countries: smoking and alcohol in Nepal (Smith 1994b), smoking in Sierra Leone (Collier 1993), heredity in Hong Kong (Allan *et al.* 1979), excess smoking, excess

drinking and heredity in the Philippines (Nichter 1994). TB is also related to certain food (cold or hot). In many parts of the world the concept of 'hot' and 'cold' plays a role in the explanatory model (Anderson 1987). Sputum is often an indication of a 'cold' disease, while haemoptysis is a sign of excess 'heat'; thus TB may be classified in both categories (Pool 1987).

Most participants are aware that TB is contagious and 'sharing with a TB patient' is mentioned as a major source of infection. In contradiction to this statement, half of the TB patients had had contact with a known TB case but did not initially perceive themselves as susceptible to the disease. Some clearly had a different explanatory model of the disease and attributed their TB infection to exposure to cold, smoke, too much work and drinking alcohol.

The stigma attached to TB seems to discourage patients from seeking treatment and may lead to reality evasion, where a patient fails to consider that he/she has TB and resorts to self-treatment to cure his/her health problem. Similar reality evasion was found among TB patients in Pakistan, who completely rejected their diagnosis (Liefvooghe *et al.* 1995) and among TB suspects in Honduras (Mata 1985) who sought relief in self-treatment from their symptoms which they attributed to external causes such as overwork or exposure to cold.

Health-seeking behaviour in tuberculosis suspects

Health-seeking behaviour (HSB) refers to what people do, whether individually or collectively, to maintain and/or return to health. The specific steps taken are sometimes referred to as patterns of resort. In this study no single HSB pattern was revealed. Both modern and traditional medicine are consulted and there are no indications for a particular preference of either. Pragmatism in the use of traditional and/or modern health care based on practical rather than ideological perception of effectiveness of care has been observed by other authors (Sauerborn *et al.* 1989). Most people acknowledge the importance of modern medicine in TB treatment, but many confirmed at the same time their affinity to traditional medicine. Modern medicine is seen as important for the diagnosis of the disease. The community members feel that TB diagnosis and treatment require a 'specialized' level of health facilities. Health centres and dispensaries are considered inadequately equipped and/or staffed. Traditional

medicine plays a role in the different stages of the treatment and is seen as a valuable alternative if modern treatment fails. This corroborates a previous study from Kenya (Ndetei 1972).

But none of the TB patients in our study admitted to seeking help from traditional medicine. This could be an underestimation as hospitalized TB patients may have been reluctant to admit that they had consulted traditional healers. Further research is needed to assess more precisely the actual role of traditional healers in TB treatment.

Self-treatment, involving a variety of home remedies, traditional and modern drugs, is the first step in the health-seeking behaviour process. It is linked with the perception of the seriousness of the symptoms and the label the patient attaches to his/her condition (Igun 1979). Prolonged self-treatment seems to be one of the important reasons for delay of appropriate treatment (Allan *et al.* 1979; Rubel & Garro 1992). Passive case detection is based on self-reporting of the cases but many patients are unaware of the significance of their symptoms. Initial screening is done by the symptomatic person alone or in collaboration with his/her close environment. It is important to realize that this is done in the community, and not in the clinic, by lay persons who interpret symptoms and assign them severity. Interventions designed to encourage symptomatic individuals to seek appropriate medical help are therefore necessary (Rubel & Moore 1995).

Wrong diagnosis causes further delay in obtaining correct treatment. This confirms findings from a previous study in Kenya which showed that health units failed to investigate chronic coughs in a certain proportion of TB suspects (Fox 1988). Allan *et al.* (1979) also suggested that TB is not always properly investigated or accurately diagnosed in health facilities. Still, conclusions should be made with caution as information was obtained solely from the patients and no attempt was made to check their statements. An assessment of delay due to misdiagnosis at the health facilities is indicated.

The influence of the family in seeking appropriate treatment and in giving social and financial support confirms previous research findings (Collier 1993; Liefvooghe *et al.* 1995). Several key persons such as teachers, community leaders, neighbours and local health workers are mentioned as being influential in the health-seeking behaviour. Their potential has not been

R. Liefvooghe *et al.* **A Kenyan community's perception of TB**

explored thoroughly. They can provide the correct advice necessary to avoid prolonged self-treatment and could make a significant contribution to opportune referral to a TB treatment centre. Eventually they might participate in direct observed treatment (DOT).

In Uasin Gishu uncertainties concerning the full curability of TB still prevail. This is more true for rural than urban communities. In her discussion of the anthropological perspective of TB, Barnhoorn (1994) attributes the negative opinions about the curability of TB to 'echoes from the past': experiences from previous generations still influence present perceptions. The relation between HIV and TB may enhance the questioning of the curability of TB, though no clear evidence was found in this study, especially as the HIV-TB relation was brought forward by the urban participants who have a stronger belief in the curability of TB.

Doubts about the curability of TB are found in other parts of the world, even in countries with low HIV prevalence such as Nepal, where the patients perceive TB as a fatal disease (Pool 1992); or Pakistan, where many patients doubt the full curability of TB (Hendrickx 1993). Those who believe that TB may be cured feel that early diagnosis and adherence to the medical instructions are essential for total recovery. This is contradictory to the long delay before a suspect will seek medical treatment. Community members are aware that TB treatment takes a long time and believe it is rough and agonising. This negative perception may have an adverse effect on seeking medical treatment.

Attitudes towards the disease and the afflicted patients

As in many developing countries, in Uasin Gishu TB is linked with social stigma. This is reflected in the old Kikuyu illness term *murimu* which refers to the need for isolation. As shown in a previous study (Liefvooghe *et al.* 1995), stigmatization is relative to the degree of kinship and relation: the lesser the degree of kinship the stronger the stigmatization. In many cultures stigma derives from feelings of guilt and blame which surround TB (Pool 1992), but no such indications were found in Uasin Gishu. Here, social stigma seems to originate from doubts about its full curability and the perception that it is extremely contagious. For fear of infection, contact with a TB patient is avoided. Fear of isolation and segregation may have a negative effect on effective TB

control, as it may lead to rejection of diagnosis and noncompliance of treatment. Its effect on voluntary presentation and treatment delay must not be underestimated (Rubel & Garro 1992; Liefvooghe *et al.* 1995). Isolation of TB patients in TB wards increases the belief that TB is a very contagious disease. The association of TB and HIV could enhance the stigma further.

Validity of the findings

Although the study has certain limitations, the findings may be considered valid. Purposive sampling of participants was chosen rather than random sampling because it has the advantage of willingness to participate actively, resulting in a good informativeness of the group discussions. Although health-seeking behaviour patterns were inquired about in a hypothetical way ('Where would you seek help/treatment if you presented these symptoms?'), the fact that many community members related experiences of family members, friends or neighbours increases credibility. The findings also reflect the potential HSB of the community members. For operational reasons, only a group of male TB patients was included in the FGD.

Our data provide no more than a glimpse of the behavioural factors affecting TB control and the findings may only be applied to the factors studied. The study did not intend to assess other important aspects of TB control such as providers' attitudes and quality of the TB control programme. While the sample included participants from several ethnic groups of Kenya, it is not necessarily representative of the whole population of Kenya. Although the FGD method has recently been advocated as a viable stand-alone procedure (Barbour 1995), triangulation with other studies would increase the validity of the results. Presently a follow-up study, with personal interviews of all TB patients is being undertaken. The preliminary data agree with FGD findings.

Conclusions

The population of Uasin Gishu District has a reasonably good knowledge of TB. Initial clinical signs are known but often confused with other minor health problems. This knowledge forms a sound base on which to build health education messages. Different explanatory

R. Liefvooghe *et al.* **A Kenyan community's perception of TB**

models for tuberculosis exist and some deviate from the biomedical model. In some cases this deviation causes patient delay in diagnosis and treatment. Medical shopping and consultation of traditional healers are important in this respect.

TB is perceived as dangerous, difficult to diagnose and cure. Suspects thus prefer to consult hospitals and medical specialists rather than first-line health services. TB treatment is perceived as exceedingly long, agonising and cumbersome. There are doubts about its full curability. Stigmatization of TB patients may lead to reality evasion and subsequent delay in seeking professional assistance. Stigmatization is enhanced by isolation of the patients in TB wards. Some health practices and health education messages increase fear of the disease by insisting on the need for isolation of patients and separation of utensils used by TB patients.

Several key persons from the community who play a role in the referral of TB suspects could be identified. Their awareness and understanding of the TB problem could be enhanced through a short training course, after which they could serve as reference and referral persons. Health education needs to inform the public without raising additional fears. It should emphasize that TB is perfectly curable and that patients, once under treatment, become noninfectious within a few weeks. The positive side and the advantages of early diagnosis and correct treatment should be stressed. People should be made more aware of the early signs and symptoms of TB, especially in high risk groups, e.g. those who recently had contact with a known TB patient. The danger of prolonged self-treatment, if symptoms persist, and of medical shopping should also be explained.

The rate of delayed TB diagnosis and its reasons among symptomatic patients who present to a health facility requires further investigation and remedial measures. Finally, it should be stressed that health education will only be effective if health care providers understand the cultural barriers to TB control and if they create the necessary supportive environment.

Acknowledgements

We thank the members of the TB team of Uasin Gishu District Hospital for their kind co-operation and the team of the Faculty of Health Sciences, Moi University for their ongoing advice and support. Special thanks go to the FGD moderators and translators Mrs. Ruto

Cheptoo Rose, Mrs Tanui Jerono Prisca T. and Mr Chepchieng Micah for their remarkable dedication to the study and to Mrs. Maru L. for the onerous work of typing out the focus group discussions.

Thanks to Dr M. Boelaert, Dr C. Suetens, Dr N. Buziba and Dr L. Janssens for their valuable suggestions. Special thanks to both referees for their critical comments. We extend further our gratitude to the Damien Foundation and the Belgian Foundation for Scientific Research (NFWO) for sponsoring the research.

References

- Allan WGL, Girling DJ, Fayers PM & Fox W (1979) The symptoms of newly diagnosed pulmonary tuberculosis and patients' attitudes to the disease and to its treatment in Hong Kong. *Tubercle* **60**, 211-223.
- Anderson EN Jr (1987) Why is humoral medicine so popular? *Social Science and Medicine* **25**, 331-337.
- Barbour RS (1995) Using focus groups in general practice research. *Family Practice* **12**, 328-334.
- Barnhoorn F & Adriaanse H (1992) In search of factors responsible for non compliance among Tuberculosis patients in Wardha District, India. *Social Science and Medicine* **34**, 291-306.
- Barnhoorn F (1994) Tuberculosis in antropologisch perspectief. Waarom tbc-patiënten geen medische hulp zoeken. *Medische Antropologie* **6**, 242-261.
- Bash CE (1987) Focus group interviews: An under-utilised research technique for improving theory and practice in health education. *Health Education Quarterly* **14**, 411-448.
- Centers for Diseases Control and Prevention (1995). *Improving tuberculosis treatment and control: an agenda for behavioral, social, and health services research*. Proceedings of Tuberculosis and Behavior: National Workshop on Research for the 21st Century. Aug 20-30, 1994; Bethesda (MD). Atlanta CDC.
- Collier H (1993) Tuberculosis patients' compliance with SCC under routine programme conditions in Sierra Leone. *MPH Dissertation. School of Tropical Medicine. Liverpool, UK* Unpublished.
- Comstock GW (1994) Tuberculosis: Is the Past once again Prologue? *American Journal of Public Health* **84**, 1729-1731.
- Coreil J, Augustin A, Holt E & Halsey NA (1989) Use of ethnographic research in a case-control study of immunization use in Haiti. *International Journal of Epidemiology* **18**, 33-37.
- Dawson S, Manderson L & Tallo VL (1993) Deciding to use focus group training. In *A manual for the use of Focus Groups. Methods for Social Research in Disease*. WHO/UNDP/TDR. (INFDC), Boston, pp. 7-11.

R. Liefvooghe *et al.* **A Kenyan community's perception of TB**

- Ezeh AC (1993) The influence of spouses over each other's contraceptive attitudes in Ghana. *Studies in Family Planning* **24**, 163-174.
- Feyisetan K (1994) Focus Groups. In *Qualitative research Methods. Teaching Material from a TDR Workshop. UNDP/ WORLD BANK/ WHO Special Programme for Research and Training in Tropical Diseases (TDR)* **3**, 24-28.
- Fox W (1988) Tuberculosis case-finding and treatment programmes in the developing countries. *British Medical Bulletin* **44**, 717-737.
- Godin G & Shepard RJ (1983) Physical fitness promotion programs: effectiveness in modifying exercise behavior. *Canadian Journal of Applied Sport Sciences* **8**, 104-113.
- Godin G (1989) The effectiveness of interventions in modifying behavioral risk factors in individuals with coronary heart disease. *Journal of Cardiopulmonary Rehabilitation* **9**, 223-236.
- Grange J & Festenstein F (1993) The human dimension of tuberculosis control. *Tubercle and Lung Disease* **74**, 219-222.
- Hendrickx E (1993) *Elaboration d'un score de risque et de prédiction de la non-observance des traitements antituberculeux à l'hôpital Bethania, Sialkot, Pakistan*. Msc Dissertation in Biomedical Tropical Sciences. Institute of Tropical Medicine, Antwerp.
- Igun UA (1979) Stages in Health-seeking: a descriptive model. *Social Science and Medicine* **13A**, 445-456.
- Jaffre Y & Prual A (1994) Midwives in Niger: An uncomfortable position between social behaviours and health care constraints. *Social Science and Medicine* **38**, 1069-1073.
- Johnson MP & Helitzer-Allen D (1995) Public Education in Tuberculosis. In *Improving Tuberculosis Treatment and Control. An Agenda for Behavioral, Social, and Health Services Research*. Proceedings of Tuberculosis and Behavior. National Workshop on Research for the 21st Century. Aug 20-30, 1994; Bethesda (MD) Atlanta CDC, pp. 129-136.
- Khan ME & Manderson L (1992) Focus groups in tropical research. *Health Policy and Planning* **7**, 56-66.
- Kitzinger J (1994) The methodology of Focus Groups: the importance of interaction between research participants. *Sociology of Health & Illness* **16**, 103-121.
- Kitzinger J (1995) Introducing focus groups. *British Medical Journal* **311**, 299-302.
- Kleinman A (1980a) Orientations 3. In *Patients and Healers in the Context of Culture*. University of California Press, Berkeley, pp. 105-107.
- Kleinman A (1980b) Family based popular health care. In *Patients and Healers in the Context of Culture*. University of California Press, Berkeley. p 199.
- Kochi A (1991) The global tuberculosis situation and the new control strategy of the World Health Organisation. *Tubercle* **72**, 1-6.
- Liefvooghe R, Michiels N, Habib S, Moran MB & De Muynck A (1995) Perception and social consequences of tuberculosis: a focus group study of tuberculosis patients in Sialkot, Pakistan. *Social Science and Medicine* **41**, 1685-1692.
- Mata JI (1985) Integrating the client's perspective in planning a tuberculosis education and treatment program in Honduras. *Medical Anthropology* **9**, 57-64.
- Ministry of Health Kenya (1993) National Leprosy and Tuberculosis Programme. *Annual Report*.
- Morgan DL & Kreuger RA (1993) When to use focus groups and why. In *Successful Focus Groups* (Ed. by LD Morgan) Sage, London., pp. 1-19.
- Murray CJL Styblo K & Rouillon A (1990) Tuberculosis in developing countries: Burden, intervention and cost. *Bulletin of the International Union against Tuberculosis* **65**, 6-24.
- Ndeti K (1972) Sociocultural aspects of Tuberculosis defaulting: a case study. *Social Science and Medicine* **6**, 397-412.
- Nichter M (1994) Illness semantics and international health: the weak lungs/TB complex in the Philippines. *Social Science and Medicine* **38**, 649-663.
- NLTP Guidelines. (1993) *National Leprosy and Tuberculosis Programme*. Ministry of Health, Nairobi, Kenya.
- Nunn PP & Enarson DA (1994) Tuberculosis - from neglect to control. *Transactions of the Royal Society of Tropical Medicine and Hygiene* **88**, 129-131.
- Palm L & Windahl S (1988) Focus groups, some suggestions. *Scandinavian Journal of Primary Health Care* **1**, 91-95.
- Pool HM (1992) *Illness behaviour and utilisation of the INF clinic in Surkhet, Nepal*. Dissertation. MSc in Health Education and Health Promotion. Metropolitan University Leeds.
- Pool R (1987) Hot and cold as an explanatory model: the example of Bharuch district in Gujarat, India. *Social Science and Medicine* **25**, 389-399.
- Rubel AJ & Garro LA (1992) Social and cultural factors in the successful control of tuberculosis. *Public Health Reports* **107**, 626-636.
- Rubel AJ & Moore CC (1995) Recommended Sociobehavioral Research for more successful Tuberculosis Control. In *Improving Tuberculosis Treatment and Control. An Agenda for Behavioral, Social, and Health Services Research*. Proceedings of Tuberculosis and Behavior. National Workshop on Research for the 21st Century. Aug 20-30, 1994, Bethesda (MD). Atlanta CDC, pp. 47-51.
- Sauerborn R, Nougara A & Diesfield HJ (1989) Low utilisation of community health workers: results from a household interview survey in Burkina Faso. *Social Science and Medicine* **29**, 1163-1174.
- Smith I (1994a) Tuberculosis: the role of culture and sensitivity? *Bulletin of Tropical Medicine and International Health* **3**, p5.
- Smith IM (1994b) *Women and tuberculosis: gender issues and*

R. Liefvooghe *et al.* **A Kenyan community's perception of TB**

tuberculosis control in Nepal. MPhil Thesis, Nuffield Institute for Health, UK.

Sudre P, ten Dam G & Kochi A (1992) Tuberculosis: a global overview of the situation today. *Bulletin of the World Health Organisation* 70, 149–159.

Sumartojo E (1993) When Tuberculosis Treatment Fails. A Social Behavioral Account of Patient Adherence. *American Review of Respiratory Disease* 147, 1311–1320.

Thomas SB (1990) Community health advocacy for racial and ethnic minorities in the United States: issues and challenges for health education. *Health Education Quarterly* 17, 13–19.

Westaway MS & Wolmarans L (1994) Cognitive and affective reactions of black South Africans towards tuberculosis. *Tubercle and Lung Diseases* 75, 447–453.

Appendix 1**QUESTION GUIDE FOR TB PATIENTS**

- Can you explain for which condition/disease you have been hospitalized? What do you know about this condition/disease?
- Do you know/use other names for this condition/disease? If yes, explain their meaning
- How did your condition/disease come about? What do you believe caused your health problem?
- How long ago did your health problem start? What were the first signs/symptoms of your condition?
- When your problems started, to whom did you go initially? Did you feel better? If not, what did you do next? Why?
- Who advised you to seek help with the health care provider/s mentioned above?
- For how long do you think you will have to take your medicine before you will be fully cured?
- What do you feel are the chances that your condition will be cured?

- How did you respond (react) on being informed about your condition? (TB)
- What was your family's reaction on receiving the news of your condition?
- What do you think will be the likely reaction of your community members on knowing your condition?
- Did you observe a change in behaviour towards you from the community when they got to know your condition?

Appendix 2**QUESTION GUIDE FOR COMMUNITY MEMBERS**

- Someone I know told me he/she has tuberculosis. What do you know about this disease?
- Which other names do you know/use for this disease? What is the meaning of these names?
- Could you tell me how a person gets tuberculosis? (Probe for all possible causes)
- How would a person know/recognize he or she has tuberculosis? (Probe for all possible signs and symptoms)
- If a person feels ill with (signs/symptoms mentioned above) where would he/she seek help?
- If he/she does not get better, what would they do next? (Probe for all possibilities and a complete picture of health-seeking behaviour)
- Who are the persons who would advise this sick person to seek help?
- Do you have an idea of how long it would take to cure tuberculosis? What do you know about the treatment?
- Do you believe tuberculosis is curable? Why?
- What is the normal handling of a TB case in your community?