## Social and Cultural Factors in the Successful Control of Tuberculosis

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Synopsis .....

The burden of tuberculosis on the public health is staggering. Worldwide, annual incidence of new

cases is estimated to be about 8 million. Almost 3 million deaths occur yearly. Early case identification and adherence to treatment regimens are the remaining barriers to successful control. In many nations, however, fewer than half those with active disease receive a diagnosis, and fewer than half those beginning treatment complete it.

The twin problems of delay in seeking treatment and abandonment of a prescribed regimen derive from complex factors. People's confusion as to the implications of the tuberculosis symptoms, costs of transportation to clinic services, the social stigma that attaches to tuberculosis, the high cost of medication, organizational problems in providing adequate followup services, and patients' perception of clinic facilities as inhospitable all contribute to the complexity. Sociocultural factors are emphasized in this report because hitherto they have not been adequately explored.

Salient among those sociocultural factors is the health culture of the patients. That is, the understanding and information people have from family, friends, and neighbors as to the nature of a health problem, its cause, and its implications. A knowledge of the health culture of their patients has become a critical tool if tuberculosis control programs are to be successful. Several anthropological procedures are recommended to help uncover the health culture of people served by tuberculosis clinics.

TUBERCULOSIS CONTINUES TO RANK among the world's most serious health problems despite the unparalleled biomedical achievement of effective prophylaxis and chemotherapy (1-4). Authorities conservatively estimate that 8 million new cases of tuberculosis occur every year throughout the world (4). Because of the poor distribution of clinical services and the difficulties that the sick encounter in gaining access to and effectively using health services, only about half of these new cases are ever diagnosed (2). Even industrialized countries like the United States and Japan, where the disease

was once under control, are experiencing an increase in cases (2,5,6). Worldwide, an estimated 3 million deaths are annually attributed to tuberculosis (4,7).

Because clinical facilities and personnel in developing countries tend to be concentrated in urban areas, tuberculosis, formerly considered a disease of crowded, economically depressed, urban neighborhoods, is now as much, if not more, of a problem in the countryside as in the cities (8). For example, in a rural area of India with inadequate facilities for the treatment of tuberculosis, the

mortality rate is 90 per 100,000 population; the metropolis of New Delhi, with vastly more adequate health facilities, boasts a far lower tuberculosis mortality, approximating 40 deaths per 100,000 population (8).

To counteract the large numbers of patients unable to sustain long term (12-18 months) drug therapy, major research and development efforts have been invested to provide efficacious, shorter term treatments (2,9). The resultant 6-month regimens for both prevention and management of pulmonary tuberculosis prove 91-94 percent effective when they are followed properly. Moreover, after completion of these treatments, few patients will experience a recurrence (1,2). However, short-course regimens are costly. In some developing nations, it is economically and logistically unfeasible to provide this type of intensive supervised care as routine treatment on a large scale (3,4).

The combined high cost of medications and the difficulties in providing followup services enable more people with active disease to contribute to the reservoir of infection, while those who had discontinued treatment develop increased drug resistance. A separate but related problem is the lengthy delay before those suffering active disease seek professional attention. Despite occasional calls for further "research on the cultural and behavioral factors that influence patient compliance," despite the fact that most programs attribute incomplete chemotherapy to patients' nonadherence, and despite the fact early casefinding is essential to breaking the chain of transmission and controlling the disease, reasons for patient default and long delays in seeking treatment have received little study (4,10).

Although patients' understanding of their symptoms and their assessment of available health care resources are widely acknowledged as crucial to tuberculosis control, the quest for a new curative "magic bullet" continues to be emphasized. This contradiction is underscored by responses to a recent survey of Mexico's State TB control directors, conducted by Dr. Rolando Collado.

Asked, "to what do you attribute the problematic nature of tuberculosis control in your jurisdiction?" the directors overwhelmingly laid the problem at the door of their patients' shortcomings: "poverty," "lack of education," "poor motivation," "superstition," and "failure to comprehend the importance of compliance with treatment recommendations." When subsequently asked, "what would you do if it was within your power to find ways to resolve this problem?" the consistent reply was, "invest resources in the search for a

new, improved medication." The same inconsistency is repeatedly revealed in the health policies of many nations as the search continues for a pharmacological solution to a far more complex problem (11-15).

Contributing to the complexity is the fact that the health culture of the population at risk of tuberculosis differs from that of clinical staff members. We call the health culture the information and understanding that people have learned from family, friends, and neighbors as to the nature of a health problem, its cause, and its implications. Sick people use their health culture to interpret their symptoms, give them meaning, assign them severity, organize them into a named syndrome, decide with whom to consult, and for how long to remain in treatment.

In this paper we address the paradox of the continuing importance of pulmonary tuberculosis as a contributor to morbidity and death, given the availability of efficacious short-course chemotherapy. We discuss some of the social and cultural reasons for this situation and suggest an approach that can lessen default from treatment and help facilitate early case detection.

#### Sociocultural Research Models

How people who are symptomatic actively cope with tuberculosis has received little attention. One early effort linked the willingness of a sample of Americans to seek preventive chest X-rays to a perception of their susceptibility to the disease and their belief in the unique value of preventive chest X-rays to inform them of the presence of disease (16). In subsequent, more experimentally designed research, a sample of healthy people was shown films on tuberculosis and several other diseases designed to increase their perceived susceptibility to the diseases and to promote the value of preventive care. Eight months after seeing the films, members of the group proved significantly more likely to have obtained a preventive examination from their physician than a control group that had not seen the films (17).

The success of these early studies contributed to construction of the Health Belief Model (HBM) (18,19). The HBM predicts that the response of people to a threatening illness depends on four factors: (a) do they believe themselves susceptible to the condition, (b) how severe do they think the illness is, (c) what benefits do they think can be obtained by taking preventive action, and (d) how costly do they perceive the barriers to obtaining

that assistance to be. Unlike the earlier studies on tuberculosis, however, the HBM sought to explain and predict health behavior in general. It was later broadened to predict also adherence to treatment without regard to the nature of the illness (20). Subsequent efforts to validate the model on North American samples have proved successful.

The relevance of HBM to tuberculosis care is apparent, although few studies have sought to assess what triggers a person to take action and when, which is so important an issue in efforts to curtail the transmission of tuberculosis. It is important to realize that validation of the HBM model has been almost exclusively carried out in North America and its applicability in other cultural settings has yet to be established.

Other research on health behavior has emphasized the influence of membership in an ethnic group on the interpretation of symptoms that trigger the search for care. Researchers found that, rather than the symptoms themselves, it is the varying interpretation of their meaning and what they imply for a functioning social life that motivates group members to seek care (21,22). Still other investigations emphasize analyses of the helpseeking pathways that patients follow after their acknowledgement of sickness to their request for professional assistance (21-23). Patients' interpretations of symptoms, decisions on when and from whom to seek help, and their response to medical regimens conform to their own explanatory model of what's wrong (24-30).

Nevertheless, health care providers often do not recognize this. Patients' efforts to cope with symptoms, or adapt treatment recommendations to the apparent course of the disease, such as lessening discomforting symptoms, are often construed by providers as ignorance, lack of concern, vacillation, or non-adherence (31).

## The Enigma of Adherence

A key to successful tuberculosis control is patient adherence to treatment recommendations (1,32-34). While the obstacles described as barring effective control are often identified as the costliness of medication, lack of access to or cost of transport, the maldistribution of clinical facilities, or shortage of trained staff are important, the list is incomplete. When considered in interaction with sociocultural factors, they may help explain mass abandonment of tuberculosis treatment. Yet, as we indicated previously, few studies have analyzed the impact of sociocultural factors on adherence to

tuberculosis treatment. Those discussed in this report and others that stress the importance of adapting services to patients' lifestyles are generally ignored in the tuberculosis literature, even in those papers that specifically demonstrate or discuss problems of adherence to treatment. This omission is puzzling, since several programs have published reports demonstrating improvement in patient adherence to treatment recommendations or greater success in reducing rates of tuberculosis after studying and taking into account sociocultural obstacles. Given that the development of new and better drugs has not solved critical remaining barriers in tuberculosis control, another look at these studies is warranted.

In the following case studies three specific topics are emphasized: (a) perception and interpretation of tuberculosis symptoms that trigger the search for medical care, (b) the influence of social stigma on help-seeking and adherence to therapy, and (c) adherence to treatment recommendations. Finally, the implications of these findings for tuberculosis control programs will be discussed.

#### Perception and Interpretation of Symptoms

There is a large body of clear documentation on how cultural understandings, sometimes explicitly, sometimes more subtly, influence people's initial acknowledgment of changes in their physical or mental well-being (35-37). Those important understandings are linked to the decision as to when, and from whom, to seek assistance (24-26.29.30).

Searching for a feasible alternative to massive, expensive case detection and control programs, researchers in rural India sought to determine the relationship among subjective levels of concern about symptoms, a decision to seek assistance, and laboratory finding of active disease (37). The index symptoms used were cough of more than 1 month, fever for more than 1 month, chest pain, and cough with blood. Those found to have been "merely conscious" or "worried aware" about their symptoms (a) had sought medical care and (b) were diagnosed with active disease confirmed by laboratory findings.

The authors concluded that the level of concern of more than half of those found by laboratory test to be sputum-positive and more than one-third of those with radiologically active disease had motivated them to seek help at government medical institutions. Researchers elected not to specify the length of time people delayed before seeking such assistance or from whom the other "worried

aware' people with symptoms sought help. Elsewhere, in two of India's major cities, it was found that 90 percent of people diagnosed as infectious had previously initiated action themselves because of their symptoms (38). These studies indicate that Indians with tuberculosis will seek professional medical care in response to their early symptoms, although the duration of time they remained reservoirs of infection before seeking care was not reported.

It would be important to know why large proportions of those suffering and acknowledging symptoms failed to seek care from biomedical facilities. Did they perhaps actively solicit care for themselves from relatives or friends, or embark on pilgrimages to health giving shrines, or seek assistance from traditional healers? Regardless of whom these ill people requested assistance from, we would wish to know what specifically triggered their decision to seek help, or why, at that time. Notwithstanding such lacunae, these pioneering researchers were encouraged enough to recommend identifying Indians with symptoms by household surveys and to refer them for bacteriological testing of sputum.

In contrast to the findings in India, a different self-initiated response to symptoms characterized people of Mexican descent in both Texas and California. In each of these locations, such responses resulted in lengthy delays before the symptoms were brought to a physician. In south Texas, delays were attributed to diagnoses by laymen of the symptoms of the folk illness, susto, a condition not considered susceptible to the ministrations of physicians (39,40).

A study was carried out subsequently among undocumented Mexican workers residing in Orange County, CA. The respondents were currently under treatment for tuberculosis and considered highly compliant by nurses of the county health service. The length of their residence in the United States ranged from 7 months to 20 years. Among these compliant patients, the average delay between acknowledgement of symptoms and the presentation of a complaint to a physician was 8 1/2 months. Whereas all of these respondents acknowledged that loss of weight, back pains, intermittent headaches, coughing, fatigue, or running nose were troublesome and usually indicative of illness, none had felt such symptoms warranted a physician's attention. Instead, all attributed the symptoms to the more benign conditions gripe (grippe) or bronquitis (bronchitis), while a few attributed them to the folk illness, susto. Although these patients did not consider the possibility that tuberculosis was the cause of their symptoms, all had eventually sought help from physicians.

All the California respondents began their treatment with self-care. Because most of the men attributed their fatigue and weight loss to hard work and lack of sleep, self-treatment consisted of retiring earlier, smoking and drinking less, and leading what they perceived to be a healthier lifestyle. The women also began self-treatment with attempts to sleep longer hours. These men and women respondents also engaged in self-care, to no lasting effect, by the purchase of over-the-counter remedies for gripe or bronquitis.

Two had been treated by lay curers for the same symptoms prior to coming to the United States. Two others, while residing in California, had attributed their condition to susto but were unable to locate appropriate lay healers. In sum, it is significant that in a group of patients considered highly compliant by the county health agency, none attributed their early symptoms to tuberculosis, and all experienced unduly long delays before seeking professional treatment. Interestingly, interviews with these patients show a continued denial of their diagnosis of tuberculosis despite faithful adherence to lengthy treatment regimens and extensive education by clinical staff members.

Other studies of the cultural understanding of tuberculosis by the Spanish-speaking population show considerable variance, reflective of diverse ethnic provenances (41-43). Differences were also found when comparing Spanish speakers and others (41-44). An unpublished study by Robinson and Eisenman reports that in Los Angeles, 37 percent of an opportunistic sample of Latinos preferring to respond in Spanish, but only 22 percent of those responding in English agreed with the statement, "if you keep your body clean, you will not get TB."

An earlier study comparing Latino respondents with Anglos and blacks in Florida found the Latino group more similar to the Anglos than to blacks (41). Using an adaptation of the semantic differential to compare how the three groups evaluated tuberculosis, the Latinos and Anglos tended to judge the disease as mild, slow-moving, clean, attacking without regard to the "goodness" of an individual, and well understood by science. The blacks understood tuberculosis as fast-moving, powerful, mysterious, and little understood by science. Blacks adjudged it a dirty disease, one that tends to attack "bad people." These different cultural understandings suggest differential behav-

ior in response to tuberculosis symptoms and clinical care services (42-44).

In the Philippines, cultural understanding of the disease affects the care of tubercular children (45). Parents attribute their children's respiratory symptoms to the folk illness, piang, rather than to pulmonary tuberculosis, bronchial asthma, pneumonia, or bronchitis. Such a lay diagnosis leads to long delays before tubercular children are brought to a physician. Traditional healers—manghihilots—are the specialist of choice; their cure for piang rests on massage to redress presumed injury to the skeletal or muscle system. Parents' attributions of the respiratory symptoms to skeletal or muscular trauma also contributed to the relatively high number of tubercular children removed from hospitals against medical advice.

The interpretation of symptoms may also have a bearing on whether patients remain in treatment. A followup study in India suggests that patients who reported more knowledge about the duration of tuberculosis symptoms and duration of treatment were more likely to complete a short-term course of chemotherapy (46). Greater interaction with health care providers for those completing the entire treatment could help to account for the differential judgements. It was also found that patients reporting more symptoms were more likely to complete the therapy and more likely to report greater improvements in health with treatment, underscoring the importance of symptoms and their amelioration in activating responses to continue the regimen (46).

#### Social Stigma and Tuberculosis

In many cultures, the largely unremarked social stigma of tuberculosis contributes to abandonment of treatment and lengthy delays in seeking professional care. The now classic effort by the Polela Health Centre to improve Zulu health using the precepts of social medicine anticipated difficulties (47). Some difficulties were surmounted, but pulmonary tuberculosis proved intractable because of its associated social stigma. "It has been the general experience at the Centre that even though an individual may have been attending the clinical sessions at the Health Centre for several years, an announced diagnosis of tuberculosis would terminate attendance," according to Cassell (47).

Furthermore, to suggest that a person with an index case possessed the power to spread disease was tantamount to identifying that person as a witch or sorcerer. In that community, only sorcer-

ers and witches had such power, and since the power to bewitch is passed through familial lines, identification of one family member as a "poisoner" implicates others. Similarly, in East Africa, attribution of tuberculosis symptoms to witchcraft or other folk illnesses is associated with delays in seeking professional treatment as well as remarkably high rates of default once treatment has begun (48).

More recently, a Mexico City survey of patients hospitalized in the San Fernando Hospital for men and the Baltasar Izaguirre Rojo Hospital for women reported how social stigma affected patients' familial relations (49). The vast majority of the respondents were illiterate, with only a few having completed the primary grades. Participants in the study came from throughout Mexico. Their average length of hospitalization was 15 months. Fifteen percent of these patients expected to be rejected by their families when they returned home from the hospital. They proved unduly optimistic. On discharge, 52 percent were not received in their homes principally due to the hostility of their families. The longer the hospitalization, the less likely that patients regained admittance to their household (49). A study of ambulatory patients in Mexico City showed that those who had abandoned treatment ascribed their default to the costs of transportation to clinic facilities, a dread of family disintegration, and fear of rejection by their relatives, in that order. Of those who had defaulted, 25 percent had failed to tell their families of their tuberculosis diagnosis, whereas only 3 percent of a comparison group remaining in treatment had not informed their families (44,50,51).

On Mexico's border with California, tuberculosis control officers report that women who have absconded from treatment break into tears at the possibility of their husband's learning of their diagnosis. Such reactions motivated the public health authorities to distribute a circular to staff members, part of which says in translation (52):

In our daily contacts with tubercular patients, we observe that despite the scientific progress won to prevent and cure this disease, society still flees from patients, avoids direct contact with them, and closes doors in their face so as to leave them isolated and without opportunity. Their own families abandon them to their fate, without a home, without help, or affection. This is a crime in view of the discovery of medication which directly acts against the TB germ. Things must change. . . .

In an unpublished study among Mexican immigrants in California, Rubel reported that the fear of social stigma strongly figured in patient's perceptions of their illness and its implications. Many patients had not mentioned to those with whom they lived the nature of their illness, others curtailed contacts with family and friends with whom they had enjoyed extensive relationships, and still others expressed fear that a spouse would discover their illness, refuse to eat or sleep with them, and even sever the relationship. One of the most striking features of these interviews was the systematic avoidance by respondents of the term "tuberculosis," an illness label familiar to the patients and consistently used by the county nurses and physicians who manage their treatment. The social stigma may well explain why so few of these patients would suggest to a coworker or acquaintance displaying the same symptoms that they may suffer from tuberculosis.

Elsewhere in southern California, an unpublished study by Robinson and Eisenman reports that 54 percent of a bilingual, opportunistic sample electing to respond in Spanish felt that their neighbors would "think less of you" if they knew you suffered tuberculosis, and 48 percent felt that their friends would have the same reaction. Those high proportions contrast with only 9 percent of an English-speaking Latino comparison group who responded similarly.

Looking at the issue from the opposite perspective in terms of degree of social support, Barnhoorn and Adriaanse, in a followup study of patients receiving treatment for tuberculosis in India, found that the successful completion of treatment is associated with social support from both family and health care providers. Those who dropped out of treatment were more likely to feel that others had shunned their company, and they had tended to isolate themselves more from others (46).

#### **Adherence to Treatment**

The retention of patients in treatment is particularly vexing in nations, regions, or neighborhoods where levels of formal education are low, difficulties and costs of transportation to clinic settings are onerous, patients lack funds with which to access clinical care while experiencing loss of income-producing labor during clinic visits, and the organization and administration of health care is problematic. The effect of such multiple interacting treatment barriers can be inferred from an account

by Friemodt-Moller of an effort mounted in India to care for village dwellers with tuberculosis (53):

The treatment began when a sufficient number of patients had been collected to justify sending out a drug-issue team the long distances. To begin with, there was an interval of 2 months from the time the sputum was found positive until treatment began. Forty-seven patients died before the treatment could begin, 14 left the towns, 20 refused treatment from the beginning, 26 stopped after the first or second drug issue, two preferred to take their own drugs. . . .

Although the acclaimed short-course chemotherapies lasting 6 months were intended to relieve such problems, significant proportions of patients with active disease, often approaching one-half, abscond from treatment before the end of 6 months. Many in fact leave treatment so early that they fail to receive any benefit whatsoever (3-5,52-59). Whereas efforts continue to shorten recommended treatment regimens to 3 or 5 months, such efforts would not help the many who abandon treatment within 3 months. Discontinued or irregular chemotherapy provides patients insufficient medication to eradicate Mycobacterium tuberculosis. Moreover, discontinuous chemotherapy or ingestion of some, but not all, components of a multidrug regimen enhance the likelihood of acquired drug resistance and incurability of the disease (3,33).

Although endeavors to retain more patients in treatment by searching for new combinations of medications are the very core of the biomedical tradition, investigation of patients' preferred modes of treatment or of their understanding and explanations of the disease that encourage or discourage seeking biomedical care, are not.

Confronted by the obstacles that their patients perceive in gaining access to prophylaxis or treatment, successful programs have adapted to those perceptions. Because delivery of health care is governed by time-honored traditions learned during professional training and supported by programmatic norms, however, efforts to modify attitudes and behavior of clinical staff members often meet with resistance (60-63).

Illustrative is the experience of the staff at the Chest Clinic of San Francisco's General Hospital where an unacceptably high rate (26 percent) of appointments were not kept (62). Staff members were interviewed for their assessment of the problem. They attributed irregular attendance to the

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social and cultural characteristics of the user population, "elderly patients, workers, skid-row alcoholics, the uneducated or ignorant, and those with a language barrier, such as the Chinese and Latin-Americans," claiming that such patients failed to attend the clinic as regularly as other groups.

In separate interviews, the patients made no reference to such explanations (62). They attributed missed appointments to inconvenient time and place, registration repeated at each visit, rigidity in taking patients in order of registration regardless of extenuating circumstances, prolonged waiting in overcrowded and poorly ventilated rooms, skid-row alcoholics seated next to mothers with small children, punitive staff practices in many cases, physician's use of medical and technical terminology beyond the educational or language comprehension of patients, no specific physician in charge of the patient and, finally, families not treated as a unit, but children and adults usually seen by different physicians on different days.

In addition, those of Chinese-American descent missed appointments because they could not close their shops until 10 p.m., after which the family ate dinner and socialized together. Black residents expressed resentment towards the clinic because it was located in a "white neighborhood"; it was not "their" clinic. The patients who resided in skidrow were the most problematic, missing 65 percent of their appointments. Their most common cause for missed appointments was recurrent jail terms of 15-20 days for drunkenness (62).

Results of the two sets of interviews with their discrepant results led to a decision to reorganize clinic services, decentralize TB staff members into "district teams" that were made available in the neighborhoods where patients lived during hours compatible with their work schedules. Resistance to changes in the lifestyles of staff members necessitated an in-service educational program to inform

them of patients' point of view and the implications for the program's success (63). These changes, based on the staff members' awareness of patients' social lives and cultural expectations, diminished missed appointments from 26 percent to 4 percent.

Another innovative program was in response to an epidemic of pulmonary tuberculosis on the Many Farms-Rough Rock Navajo Indian Reservation (64-66). It was initiated at a time when 33 percent of the reservation's school children younger than age 12 were tuberculin positive. The program allowed youngsters with active cases to be maintained at home among family members, allowing them voluntary access to traditional healers. The program depended on bilingual Navajo men and women who had received 6 months training in the basic biomedical concepts of health and disease to bring tuberculosis treatment and education directly to the homes of the patients. All but two of these "health visitors" had themselves been cured of tuberculosis.

The success of the health visitors offers a precedent for other programs. Adaptation of clinical and preventive programs to the health beliefs and values of the Navajo, together with improved transportation to clinics, improvements in primary school education, and greater wage-earning opportunities for parents helped diminish the level of tuberculin positivity among school age children from 33 percent to 8 percent (66).

The success among the Navajos doesn't seem to have influenced a 1984 recommendation by Pitchenik to recruit "former patients with tuberculosis (the ones who were models of compliance with drug therapy) [to] be carefully selected, indoctrinated, educated... to help administer fully supervised short-course chemotherapy" in developing countries (67). We will comment later on the curious reluctance of operators of control programs to learn from the successful experience of others (60,61).

### **Contextualizing Sociocultural Factors**

Sociocultural factors are not uniquely responsible for the persistence of tuberculosis as one of the world's major health problems. Two factors crucial to the success of multidrug chemotherapy are the cost of drugs to national programs and the assured availability to patients of all the components of the drug therapy. Even under the best of conditions, the delivery of long-term treatment based on pharmaceuticals in developing countries is problematic

(8,51,68). During times of civil unrest or fiscal crisis, ordinary logistical problems that affect delivery of medications to outlying clinics or even the purchase by government agencies of all components of a multidrug treatment program become virtually impossible.

Also inhibiting appropriate delivery of treatment is physician noncompliance with recommendations of expert committees (2,3,69,70). In the United States, a survey of 28 metropolitan health departments found 25 percent routinely hospitalizing more than half of all patients for initial treatment despite clear evidence that hospitalization failed to improve outcome (69). Some years after medical authorities recommended intensive 6-month regimens, the most widely used drug schedule remained the 18-24 months daily treatment. Although "Eleven programs [of 28 surveyed] used shortcourse (6-8 month) chemotherapy regimens . . . only 3 programs used short-course therapy for more than 10 percent of the patients." In sum, the lack of readiness of physicians and other providers to practice "clear cut advances established in well conducted clinical trials and surveys" is a matter of great concern (69).

Similarly, in England and Wales as recently as 1977-79, 70-81 percent of tubercular patients were being hospitalized, with 23 percent being admitted as routine policy despite authoritative recommendations against hospitalization (60). These factors—inadequate availability of critical drugs and laggardly implementation of treatment recommendations—act in concert with sociocultural dynamics to perpetuate the spread and persistence of pulmonary tuberculosis.

Characteristically, and with few exceptions, the existing studies of these obstacles to success have been single-tracked, fastening attention on barriers such as inadequate transportation or economic costs or on cultural differences between lay and professional explanatory models. But by and large, researchers have not sought the consequences of two or more of these factors in interaction (5). Acutely needed, therefore, are investigations that assess how people use knowledge to interpret symptoms of this chronic, debilitating disease at the time that they seek help and how their help-seeking decision is influenced by financial, transport, and other considerations (32,68,71).

More specifically, the research would seek to reveal those processes by which people define themselves as ill, how they select from treatment options during the initial stages of illness, and how they decide to continue or discontinue chemotherapy. Such research also would attempt to learn what triggers decisions by the ill to obtain biomedical help at the time they seek it, and the socioeconomic constraints they perceive as barriers to seeking and adhering to treatment.

Further, because it is intuitively plausible that the knowledge of tuberculosis that informs patients at the time they seek attention changes during their treatment, it is of particular importance to determine the extent to which patients' comprehension of their condition is influenced by the education that they receive from clinical staff members.

#### Recommendations

What can be done in the busy clinic setting to comprehend the local population's cultural understandings about tuberculosis and its impact on successful control of the disease? First, we recommend adopting focus group sessions for patients to develop those preventive and treatment procedures most appropriate for the clinic's own catchment area (72).

In these sessions a small group of patients, representative of those using the clinic's services, informally discuss their opinions and ideas about the causes, prevention, and cure of tuberculosis, as well as their appraisal of the clinical services. Sessions best consist of 6-12 persons and a facilitator who is of the same cultural background, but not a clinical professional. Moreover, to encourage the open expression of opinions and ideas, sessions should be held in a school, a church, a community center, or someone's home or yard, rather than in the clinic.

Questions by the facilitator are designed to open up discussion and the uninhibited airing of opinions. That is, the educational experience is designed to inform the clinical staff of the population's cultural perspectives of tuberculosis rather than the reverse. Some illustrative questions to ask of these groups follow:

- Tell me, what are some of the conditions that are associated with pain in the back and shoulders? What are some of the conditions that are associated with coughing and runny nose?
- Are some of these conditions more serious than others?
- Have you known anyone with back and shoulder pains, or who has been coughing for longer than 2 weeks?
- What did they do about their condition? What would you have done? Why?

- Have you heard of tuberculosis?
- Can you tell me what you know about it?
- Do you remember how or where you learned about it?
- Are there ways of preventing tuberculosis? Can it be cured?
- What do you think is the best way to inform the neighborhood about tuberculosis and what can be done to prevent and cure it?

We also recommend that at the time the patient is told of the definitive diagnosis of tuberculosis, the case manager ascertains the patient's own view of the problem, its causes, implications, and the patient's expectations for treatment. This will permit the case manager to develop a regimen tailored to the perceived needs, concerns, and work schedule of the individual patient, assuring greater likelihood of adherence to a full course of treatment. We recommend for this purpose the L.E.A.R.N procedure (73).

## **Conclusions**

In this review we have discussed factors militating against successful tuberculosis control despite the remarkable efficacy of short-course, multidrug regimens. Impediments such as the cultural understandings that people with symptoms apply to their disease, staff reluctance to adapt their work environments to patients' daily activities, and the sociopolitical organization of health delivery services have been emphasized because their influence has received little study. We have sought to show that a comprehensive analysis of the health culture of groups at high risk of this disease as it interacts with the availability of effective chemotherapy will provide the needed groundwork for vanquishing remaining barriers to successful, enduring tuberculosis control.

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# Czechoslovakia's Changing Health Care System

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# Synopsis .....

Before World War II, Czechoslovakia was among the most developed European countries with an excellent health care system. After the Communist coup d'etat in 1948, the country was forced to adapt its existing health care system to the Soviet model. It was planned and managed by the government, financed by general tax money, operated in a

highly centralized, bureaucratic fashion, and provided service at no direct charge at the time of service.

In recent years, the health care system had been deteriorating as the health of the people had also been declining. Life expectancy, infant mortality rates, and diseases of the circulatory system are higher than in Western European countries.

In 1989, political changes occurred in Czechoslovakia that made health care reform possible. Now health services are being decentralized, and the ownership of hospitals is expected to be transferred to communities, municipalities, churches, charitable groups, or private entities. Almost all health leaders, including hospital directors and hospital department heads, have been replaced. Physicians will be paid according to the type and amount of work performed.

Perhaps the most important reform is the establishment of an independent General Health Care Insurance Office financed directly by compulsory contributions from workers, employers, and government that will be able to negotiate with hospitals and physicians to determine payment for services.

CZECHOSLOVAKIA IS A LONG, narrow, landlocked country in central Europe, surrounded by Poland, Hungary, Austria, Germany, and a small part in the east by Ukraine. Geographically, there are three regional areas—Bohemia and Moravia in the west and Slovakia in the east—that were combined following World War I to form present Czechoslovakia. Politically, the country was divided into two

republics, Bohemia and Moravia forming the Czech Republic and Slovakia forming the Slovak Republic. Of today's total population of 15.6 million, two-thirds live in the Czech Republic and one-third live in the Slovak Republic.

As a result of the Munich Agreement in 1938 between western European powers and Germany, Bohemia and Moravia fell under German protec-