
Tuberculosis Research and Control

Anthropological Contribution

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INTRODUCTION

Worldwide, tuberculosis (TB) kills more young and middle-aged adults than any other infectious disease (WHO, 1999). Though it is curable and preventable, more than 5,000 people die of TB *every day* (2 to 3 million people per year) (WHO, 1999). TB often strikes the most vulnerable members of society and, if left untreated, causes its victims to lose weight, weaken, and eventually waste away (Ryan, 1993). TB disproportionately affects the indigent and other marginalized groups of society in whom unequal susceptibility patterns have long been recognized (Dubos & Dubos, 1952).

Many complex biological and social factors impact TB transmission, progression to disease, and treatment. By identifying and examining the interrelation of these factors, anthropologists and other social scientists have made important contributions toward the control of TB. Anthropological methods and approaches have been especially valuable in understanding and addressing the broad range of sociocultural, behavioral, and structural issues pertinent to TB control. This entry presents a review of TB-focused anthropological and social science literature included in Medline, PubMed, PsycInfo, Gale Business Arts, Web of Science, SocioFile, and Anthropological Index Online. While limited in breadth and scope, the research highlighted here has many implications and applications for TB control practice.

EPIDEMIOLOGICAL AND MEDICAL FEATURES OF TB

Epidemiology of TB

The epidemiology of TB has an unequal global distribution. The highest numbers of active TB cases are found in less developed countries, especially in Southeast Asia, which has 41% of the world's TB burden with over 3 million cases per year; in the African nations that are most affected

by HIV, there are 1.6 million new TB cases each year, in contrast with nations having established market economies, which report roughly 100,000 cases. Moreover, one third of the world's population is estimated to have latent TB infection (WHO, 2001). In industrialized nations, although the numbers of cases continue to decline, TB disproportionately affects low-income groups, substance users, persons from TB-endemic regions, the elderly, and residents of congregate facilities, such as nursing homes and prisons (ATS, 1992; CDC, 2000; Grange, 1999).

The HIV/AIDS pandemic has greatly contributed to the continuing threat of TB, particularly in Africa and Southeast Asia. In Africa, the estimated incidence of TB closely correlates with the estimated HIV prevalence (WHO, 2001); worldwide, in fact, one third of the increase in new TB cases in the last 5 years can be attributed to HIV (WHO, 1999). TB is now the leading cause of death among HIV-positive persons worldwide and accounts for 40% of AIDS deaths in Africa and Asia (WHO, 1999). In the United States, active TB is included as an AIDS-defining opportunistic infection for HIV-infected persons (CDC, 1998).

Adding further urgency to controlling TB, multidrug-resistant TB (MDRTB) has emerged as a serious problem in many parts of the world, including Russia, Latvia, Estonia, Argentina, the Dominican Republic, and the Ivory Coast (WHO, 1999). Up to 50 million people worldwide may be infected with MDRTB (WHO, 1999). In low-prevalence countries, drug resistance is generally more common in foreign-born populations, most likely reflecting inadequate treatment programs and sporadic drug availability in high-prevalence countries (Broekmans, 2000).

Medical Features of TB

TB disease in humans is a communicable disease caused by *Mycobacterium tuberculosis*. Although it can affect any part of the body, generally only active pulmonary and laryngeal TB pose a risk of

transmission from one person to another. Like influenza, *M. tuberculosis* is transmitted when a susceptible individual inhales air containing droplet nuclei carrying the tubercle bacilli. Once inhaled, the droplet nuclei eventually reach the lungs and frequently spread throughout the body. In most cases, a competent immune system limits the multiplication of the tubercle bacilli, although some bacilli remain dormant but viable, rendering a condition known as latent TB infection (LTBI) (CDC, 1995a, 2000).

A person with LTBI has an estimated 10% lifetime risk of developing active TB disease. However, certain persons, including children under 4 years of age, persons who have a weakened immune system due to conditions such as malnutrition, HIV/AIDS, diabetes, or certain cancers, and those recently infected with *M. tuberculosis*, have a much greater risk of developing active TB. HIV coinfection is the strongest known risk factor for developing active TB disease. Studies suggest that being coinfecting with HIV and TB places people at a 7–10% *per year* risk of developing active TB (CDC, 1995a, 2000).

Diagnosis and Treatment

The most widely used diagnostic method for TB is microscopic examination of stained smears of sputum, while sputum cultures usually confirm the diagnosis. Chest radiographs are commonly used to assist in diagnosis. The tuberculin skin test is used to diagnose LTBI (CDC, 1995a, 2000).

In most cases, active TB is effectively treated with a combination of four drugs taken for at least 6 months (CDC, 1995a, 2000). Treating persons coinfecting with HIV and TB is more complicated, as the appropriate treatment regimen must take into account the disease progression of the patient and interaction of drugs if protease inhibitors are involved. Treatment of MDRTB is also complicated and requires the use of more expensive and more toxic second-line drug regimens (CDC, 1995a, 2000). In developing countries, MDRTB is more likely to be fatal due to the limited availability and accessibility of effective treatments (WHO, 2000).

LTBI may be treated with one of several drug regimens. In many industrialized nations, treatment is commonly recommended for persons with LTBI at high risk of developing active TB disease (CDC, 2000), such as HIV-infected persons and contacts of TB patients.

HISTORY OF TB

Theories regarding the origins and global spread of TB continue to change as new archeological discoveries are made and molecular technologies evolve (Davis, 2000). Studies have enabled scientists to hypothesize that *M. tuberculosis* evolved from the closely related mycobacterium, *M. bovis*, possibly coincident with the domestication of cattle by humans approximately 15,000–20,000 years ago (Daniel, 2000). Studies have identified TB in mummies from Egypt dating back 5,400 years (Crubézy et al., 1998; Daniel, 1997). Skeletal remains show TB had spread throughout Europe and the Middle East during the Stone Age (Ryan, 1993). Other skeletal remains suggest that TB reached the Americas with the early migrants via the Bering Strait (Daniel, 2000), and remained a major health threat throughout the pre-colonial period.

Sociological and anthropological research has explored the social context of TB over time. Analyses of ancient writings provide amazingly accurate descriptions of persons afflicted with what we now know to be pulmonary TB (Ayvazian, 1993). The high mortality associated with TB was reflected in art, social policy, and science (Barnes, 1995; Bates, 1992; Smith, 1996; Star & Bowker, 1997; Tomes, 2000). Although the wasting pallor caused by TB became romanticized briefly during the mid-19th century (Ott, 1996; Sontag, 1990), the disease was otherwise overwhelmingly perceived to be caused by poverty, uncleanness, or immorality. Dubos and Dubos (1952) note that even in ancient times, written records and even death records may have downplayed the existence of TB, suggesting negative social stigma.

Notable advances in understanding the pathophysiology and clinical manifestations of TB occurred during the 17th, 18th, and early 19th centuries (Ayvazian, 1993). By linking the disease to its social context, scientists and political leaders advocated for social reform with mechanisms such as better nutrition, improved sanitation, and better housing to reduce the disease. Late in the 1800s, isolation and treatment of TB patients in sanatoria (Feldberg, 1995) and the pasteurization of milk to eliminate the threat of *M. bovis* were highly visible attempts to control TB. General economic development played a further role in the decline of TB mortality in industrialized nations (Fairchild & Oppenheimer, 1998).

In 1882, Robert Koch identified the tubercle bacilli, *M. tuberculosis*, as the biological cause of TB disease and established it as an infectious

disease (Ayvazian, 1993). In the 1940s, scientists discovered that the antibiotic, streptomycin, killed *M. tuberculosis*; however, the bacilli had a propensity to develop resistance to antibiotics when only streptomycin was used. By 1950, combined drug treatment was established and, a few years later, isoniazid was introduced as a “miracle” cure for TB when combined with properly chosen drug combinations for sufficient duration (Davis, 2000).

As social scientists observed, the introduction of the first antibiotics to treat TB enhanced the assumption of physicians’ expertise and authority in obviating this major public health threat. Lerner (1997) notes that by the 1950s and 1960s, researchers were using terms such as “uncooperative” and “non-compliant” to describe patients who did not follow physicians’ treatment orders. In the 1970s, social scientists began emphasizing the importance of a patient’s right to be actively involved in treatment decisions (Donovan & Blake, 1992; Stimson, 1974; Sumartojo, 1993; Trostle, 1988) as well as the pejorative implications of the term “compliance” itself, recommending the term “adherence” to better acknowledge the patient role in TB care and treatment (Ogden, 1999; Sumartojo, 1993).

Over the next decades, despite declining TB mortality rates in industrialized nations, TB continued unabated throughout most of the world. Further, the emergence of the HIV/AIDS epidemic and of MDRTB were cause for serious global concern. The need to use social and behavioral approaches to strengthen the quality of patient care became more apparent. Many programs implemented interventions such as directly observed therapy (DOT), whereby health care workers observe patients swallowing medication.

Subsequently, directly observed treatment, short-course (DOTS), was developed and promulgated by the World Health Organization as its strategy for TB control (Walton & Farmer, 2000). Concurrent with the calls from the medical community for new social and behavioral interventions has been a call in the social sciences for a better understanding of the potential impact of such interventions and to develop new intervention strategies through coordinated, theory-driven research (CDC 1995b; Farmer, 1997; IOM, 2000; Rubel & Moore, 1995).

SOCIAL AND CULTURAL RESEARCH IN TB CONTROL

In reviewing the published anthropological and so-

cial science literature on TB, wide gaps in research are apparent. Research into the meaning and social implications of TB has been limited to a relatively small number of cultures. In her recent literature review, Ogden (2000) notes that the limited use of theoretical frameworks to examine behaviors hinders full understanding of the social and cultural factors surrounding TB.

Similarly, Jaramillo (1998) found that many studies are narrow in scope and examine neither the context of TB control programs nor other external factors that may influence behavior. Jaramillo further notes that the use of different study designs and methods sometimes results in contradictory findings. Despite the lack of theoretical grounding and of reliable comparison studies that allow patterns to be identified across cultures, the published social science research provides valuable information on key issues affecting patient outcomes. Issues related to care-seeking behaviors, adherence to treatment, stigma, program structure, and patient-provider relationships are particularly important to TB control. This section has been organized to reflect this applied approach.

Understanding Care-Seeking Behaviors

Studies examining how a local culture interprets TB causes and symptoms help providers understand why people delay seeking treatment. For example, in Thailand, research indicates that some people, associating their TB symptoms with HIV/AIDS, delayed seeking treatment for fear of having AIDS (Ngamvithayapong, Winkvist, & Diwan, 2000). In Kenya, patients attributed TB to causes such as hereditary predisposition, consumption of alcohol, smoking, or witchcraft, which often resulted in delayed care-seeking at a clinic specifically for TB patients (Liefoghe, Baliddawa, Kipruto, Vermeire, & Munynck, 1997). Recent work in the Philippines showed that many patients attributed TB symptoms to drinking or smoking, and, thus, delayed seeking treatment for their “harmless” symptoms (Auer, Sarol, Tanner, & Weiss, 2000). Similarly, in a study of the Igbo of Nigeria, TB patients who held rigidly traditional views that TB can be spread by eating beef and other high-protein foods reportedly delayed seeking treatment, often waiting until after they were malnourished (Enwereji, 1999).

In Botswana, TB symptoms are often attributed to hard work in mines or to drinking and smoking (Steen & Mazonde, 1999). Some groups report

multicausal models regarding TB etiology. For example, Vietnamese refugees in the United States reported various combinations of 29 separate beliefs regarding causes of TB, the most frequent being hard manual labor, smoking, alcohol consumption, poor nutrition, and germs (Carey et al., 1997). In Malawi, patients believed TB was caused by adultery, germs, alcohol abuse, "wrong" food, stagnant water, dust, and witchcraft (Brouwer, Boeree, Kager, Varkevisser, & Harries, 1998).

Etiologic beliefs may influence how people choose to treat or be treated for their symptoms. A study in Malawi showed that patients thought TB resulted from bewitchment or breaking sexual taboos believed they could only be treated by traditional healers, while TB from other causes could be treated with Western medicine (Banerjee, Harries, Nyirenda, & Salaniponi, 2000). In contrast, other groups express strong preferences for treatment from biomedically trained physicians, with little or no interest in traditional remedies (Carey et al., 1997). In Ethiopia, interview respondents believed TB and all diseases were generally caused by imbalances in behaviors or diet, and were best treated by herbal remedies and healthy foods (Vecchiato, 1997). A study among the Xhosa-speaking people of South Africa found that people often associated TB with a lack of hygiene and also with witchcraft, specifically the lightning bird, *impundulu*, and sought care first from a diviner (de Villiers, 1991).

Only when traditional treatment failed did they seek Western medicine. Similarly, Wilkinson, Gcabashe, and Lurie (1999) reported TB patients' visits to spell casters, faith healers, and those who use plants for healing among South African patients, despite patients' recognition that TB could be cured.

In rural Haiti, while many patients accepted sorcery as a possible cause for TB, their etiological beliefs had no impact on compliance with biomedical regimens (Farmer, Robin, Ramilus, & Kim, 1991). Similarly, Rubel (1993) found high rates of adherence with biomedical treatment among migrant farm workers, regardless of whether they attributed their symptoms to biomedical causes or "folk illnesses." In Tanzania, Wandwalo and Morkve (2000) found no connection between knowledge about TB and completion of treatment. In Chiapas, Mexico, religious movements have increased the acceptance of germ theory and of Western medicine, reducing the attribution of disease to witchcraft (Menegoni, 1996).

While Western medicine offers patients a bio-

logical explanation for the biological cause of TB, it cannot provide a spiritual or philosophical explanation of why they have been afflicted with it (Steen & Mazonde, 1999). Traditional, non-Western practice offers patients meaning for their illness as well as emotional support (de Villiers, 1991; Steen & Mazonde, 1999). Further, traditional healers are easily accessible and often paid after the patient is cured (Liefoghe et al., 1997). One study in Nepal reported that women sought traditional health care services before seeking care in government clinics, due in part to the proximity of services (Yamasaki-Nakagawa et al., 2001). In Botswana, traditional healers advised TB patients to attend medical clinics when patients presented with certain signs and symptoms (Steen & Mazonde, 1999). In contrast, in Malawi, patients often sought care from traditional healers initially, but were reluctant to disclose these visits to medical professionals for fear of being denied care by Western doctors (Brouwer et al., 1998).

The importance of semantics in illness and treatment is illustrated by Nichter's work in the Philippines. The term "weak lungs" covers a range of respiratory ailments and is used by the lay population and physicians alike, the latter ostensibly to avoid the stigma associated with TB. However, broad use of the term "weak lungs" leads to self-treatment, a practice encouraged by the marketing of isoniazid as a type of "vitamin" for the lungs, considered useful even if taken for a short time. These practices can result in delayed diagnosis and the development of drug resistance (Nichter, 1994). In a study of Ethiopian refugees in Israel, Chemtob, Weiser, Yitzhak, and Weiler-Ravell (2000) found that the confusing Ethiopian terms used for TB symptoms and related illnesses increased communication problems with health care providers and treatment in Israeli clinics.

Kleinman (1980) studied the indigenous ways in which TB was viewed and explained in China, noting that local terminology merges both the psychological and physical symptoms of the disease. Using Kleinman's explanatory framework, Rubel and Moore (2001) found that working-class Mexicans from similar socioeconomic strata share a humoral explanatory model of TB (i.e., illness categorized as "hot" or "cold") and that women shared much stronger agreement on these humoral qualities than men. This finding could be explained by Mexican women's role as gatekeepers of household health and their consequent greater knowledge of health and illness, suggesting the influence of learned social roles on the dis-

tribution of traditional health knowledge.

In industrialized nations, social scientists have sought to better understand the health cultures of subpopulations. Researchers found many misunderstandings about TB among minority ethnic groups in Kansas City (Marinac, Willsie, McBride, & Hamburger, 1998). In New York, interviews with Vietnamese refugees showed misunderstandings related to TB causes and transmission (Carey et al., 1997). Similar findings were reported in a focus group study of Vietnamese persons in California, who nonetheless indicated broad trust in Western medicine (Nguyen, Yamada, Matsunaga, & Caballero, 2000). However, in Manitoba, many refugees continued to use traditional medicines (Peters, Hershfield, Fish, & Manfreda, 1987).

Ailinger and Dear (1997, 1998), working with Latino immigrants in the United States, found that concern for family motivated care-seeking behavior and adherence to treatment. Similarly, social support contributed to adherence and completion of therapy, and thus to a reduction of TB incidence among foreign-born persons in Massachusetts; however, economic and social disadvantages often outweighed protective factors. (Mitnick, Furin, Henry, & Ross, 1998). Focus groups with Philippine immigrants showed a continued belief in traditional treatments despite other aspects of acculturation (Yamada, Caballero, Matsunaga, Agustin, & Magana, 1999).

Understanding Adherence Issues

Treatment non-adherence fuels continuing TB transmission and fosters the development of drug resistance, resulting in serious risks both for the individual patient and for the community. The issue of non-adherence to TB medications has frequently been examined through varied approaches and methodologies, yielding a wide range of findings having no single predominant pattern. Many social scientists have identified patient health beliefs or health cultures as the main "cause" of non-adherence (Barnhoorn & Adriaanse, 1992, 1992; DiMatteo & DiNicola, 1981). Thompson, Snider, and Farer (1985), examining adherence rates in seven European countries, attributed differences to the extent to which "cooperativeness" as a community value cut across national cultures. Cultural perceptions of medications, such as the classification of medications into "hot" or "cold" according to humoral theory, may also influence adherence (Ito, 1999; Manderson, 1998).

Taking a broader perspective, other social scientists see the issue of non-adherence as stem-

ing from complex factors both within and beyond the control of patients. These factors include patients' confusion about the implications of symptoms, social stigma, perception of services and providers, transportation costs, the high cost of medications, and service access and delivery problems (Ailinger & Dear, 1998; Liam, Lim, Wong, & Tang, 1999; Rubel & Garro, 1992; Sumartojo, 1993; Thomson & Myrdal, 1986). Nachman's (1993) work with Haitian refugees also showed that, despite patients' trust in Western medicine's efficacy, lack of information and mistrust of service providers greatly reduced their adherence to care (1993). Researchers in India found a high default rate despite high levels of patient knowledge and care-seeking. This behavior was not determined by cultural factors, but by the operational dysfunction of the local TB program (Juvekar et al., 1995).

Considering the vast socioeconomic inequities that persist throughout the world, Farmer affirms that individuals who do not adhere to therapy are probably "the ones least able to adhere" (Farmer, 1997). A study of Latinos in California demonstrated that, while trust in TB control practices and social connections facilitated patients' adherence to treatment, access issues most affected behaviors (Poss, 1998, 2000). Similarly, in an investigation of factors affecting medication-taking behavior in central India, Barnhoorn and Adriaanse (1992) found that three socioeconomic variables, not cultural factors, were the strongest predictors of adherence: a family's per capita income, the type of house in which they lived, and the family's monthly income.

Virtually all adherence studies note the difficulties encountered in measuring adherence. Even well-designed studies have failed to find psychological correlates of adherence (Sumartojo, 1995), thus hindering the ability to predict adherence. Given these difficulties, many programs have adopted directly observed therapy as the standard of care (Chaulk & Kazandjian, 1998; Volmink, Matchaba, & Garner, 2000a, 2000b). While effective in monitoring adherence (Chaulk, Moore-Rice, Rizzo, & Chaisson, 1995; Fujiwara, Larkin, & Frieden, 1997), this often costly method of care has raised several questions to which social science has added perspective. For example, researchers questioned the extent to which TB programs have failed to recognize the socioeconomic context in which patients receive services (Diwan & Thorson, 1999; Hurtig, Porter, & Ogden, 1999; Pronyk & Porter, 1999).

The Impact of Stigma

Few would disagree that there is universal social stigma attached to TB (Farmer, 1997). Besides contributing to a worsening of the quality of life for people with TB (Hudelson, 1996; Jaramillo, 1999a), stigma plays a role in most stages of the disease – from acknowledging symptoms and seeking care to being labeled as cured (Rangan & Uplekar, 1999). By identifying the consequences of stigma, social scientists have illustrated the need for effective intervention strategies.

Numerous studies have shown patients' denial or hesitation to disclose their TB status to family or friends owing to the overwhelming fear of being socially ostracized (Chakraborty, Rangan, & Uplekar, 1995; Johansson, Diwan, Huong, & Ahlberg, 1996; Liefoghe Michiels, Habib, Moran, & De Muynck, 1995; Nair, George, & Chacko, 1997; Shrestha-Kuwahara, Wilce, DeLuca, & Taylor, 2002). Researchers reported that 77% of the Vietnamese persons studied in New York believed the community would fear and avoid persons with TB, and over 90% stated that having the disease would adversely affect TB patients' relationships with their families (Carey et al., 1997). Rubel and Garro found that fear of stigma among Mexican immigrants in California significantly influenced patients' perceptions of their illness and caused them to cease contact with family and friends (Rubel & Garro, 1992). They reported similar findings in Mexico, where patients blamed the social consequences of stigmatization—ostracism—for their long delays in seeking care and their poor adherence to treatment (Rubel & Garro, 1992). In Honduras, Mata (1985) found strong stigma associated with TB, and fear of family rejection and loss of friends led some patients to report preferring death to social rejection. In Vietnam, researchers found that cultural beliefs related to TB transmission increased stigma and isolation of patients (Long, Johansson, Diwan, & Winkvist, 1999).

Other studies have demonstrated that the shock of being diagnosed with TB frequently sends patients and their families in search of a different diagnosis elsewhere (Dick & Schoeman, 1996; Liefoghe et al., 1995; Uplekar & Rangan, 1996). In a study of Indian patients, Uplekar and Rangan (1996) noted that some doctors avoid disclosing a TB diagnosis out of fear that patients will not return. Strong stigma was similarly noted among South African Zulus who, even after attending a clinic for years, stopped attending after receiving a diagnosis of TB (Rubel & Garro, 1992). In Turkey, even the relatives of TB patients avoided contact

with TB dispensaries (Gokce et al., 1991). Stigma can also result in loss of employment, or fear of such, thus delaying care-seeking, diagnosis, and effective treatment (Carey et al., 1997; Jaramillo, 1998; Johansson et al., 1996; Shrestha-Kuwahara et al., 2002; Thomson & Myrdal, 1986).

In societies in which women occupy a lower status, the social consequences of a TB diagnosis may result in undertreatment and increased mortality (Holmes, Hausler, & Nunn, 1998; Hudelson, 1996). Studies in India have shown that married women delay seeking treatment or do not disclose their diagnosis to their husbands out of fear of being deserted (Connolly & Nunn, 1996; Nair et al., 1997; Rajeswari et al., 1999). In Nepal, the low status of women and fear of social ostracism hinder access to adequate TB care (Smith, 1996). In India and Pakistan, single women with a history of TB may face fewer opportunities for marriage (Barnhoorn & Adriaanse, 1992; Jaramillo, 1998; Liefoghe et al., 1995; Rangan & Uplekar, 1999). In Vietnam, stigma has been shown to interfere with provider relationships with female patients and hinder compliance (Johansson, Long, Diwan, & Winkvist, 1999; Long, Johansson, Diwan, & Winkvist, 1999).

Provider Behavior and Service Delivery

The trusting relationships providers form with patients have been shown to strongly influence treatment success (Pozsik, 1995; Salomão, 1999; Sbarbaro, 1990). A review of existing studies addressing provider behaviors suggested that patients respond positively to attention and encouragement (Boehm, Coleman-Burns, Christensen, & Schlenk, 1995). Similarly, a recent meta-analysis of program-level interventions showed that program success is frequently attributed to good patient–staff relationships and friendly, competent staff (Volmink et al., 2000a, 2000b).

Among the social scientists examining patient–provider interrelationships, Jaramillo (1998) demonstrated that interpersonal relationships are heavily influenced by the negative perceptions of TB patients held by health care workers. By stigmatizing the patients, providers create an unfriendly clinic environment and then blame the patients for failing to complete treatment. In Israel, Ethiopian immigrants experienced condescension and paternalism from physicians (Chemtob et al., 2000). Such unprofessional attitudes of providers exacerbate patients' hesitance to seek or remain in care (Walt, 1999). Patients in other studies reportedly

preferred interacting with the more empathetic paramedics or community volunteers, perceiving clinic nurses as authority figures (Dick, Schoeman, Mohammed, & Lombard, 1996; Menegoni, 1996). In a number of studies, researchers found that women sought care from providers they felt comfortable with rather than visiting government-run TB clinics and often delayed obtaining appropriate treatment (Long et al., 1999; Lönnroth, Thuong, Linh, & Diwan, 1999; Thorson, Hoa, & Long, 2000; Yamasaki-Nakagawa et al., 2001).

Cultural and communication gaps between patients and providers have also been explored. Studies have demonstrated that patients and providers have strikingly different perceptions of the barriers to adherence and of the communication that has been exchanged (Rubel & Garro, 1992; Shrestha-Kuwahara et al., 2002). Rubel and Moore (1995) theorized that gaps between patients' and providers' perceptions about interactions and care resulted in the use of poor information for policy planning. Moreover, a lack of understanding of the cultural differences in attitudes can diminish the trust between physician and patient (Grange & Festenstein, 1993).

Fueling patients' mistrust, major deficiencies have been found in physician knowledge, attitudes, and practices in appropriate TB management and in dissemination of information to patients (CDC, 1994; Thomson & Myrdal, 1986; Uplekar & Shepard, 1991). Inaccurate knowledge of TB transmission or appropriate treatment regimens may result in misdiagnosis or mistreatment (Lienhardt et al., 2001; Mata, 1985; Nair et al., 1997; Sumartojo, Geiter, Miller, & Hale, 1997). Interviews with patients in Pakistan confirmed that patients lacked confidence in TB treatment because of poor service and scarce or inaccurate health information (Khan, Walley, Newell, & Imdad, 2000).

Program Structure

The impact of program structure on patient behavior was acknowledged some 30 years ago when Dr. Francis Curry in San Francisco increased patients' clinic visits via expanded clinic hours and reduced wait times. Although few scientists have examined the overall dynamics of the sociopolitical and economic environment of TB control (Grange & Zumla, 1999; Rubel & Moore, 1995; Walt, 1999), social scientists have shown that program structure and systems organization can have a major impact on TB care.

Although limited, research has shown the effectiveness of comprehensive health service sys-

tems that address core issues behind TB risk factors, such as overcrowding, malnutrition, and limited access to health care services. In Haiti, Farmer showed how comprehensive health and social services can successfully reduce mortality and drug resistance (Farmer, 1997; Farmer et al., 1991). In Mexico, policy interventions addressing structural barriers resulted in improved patient adherence (Rubel & Garro, 1992). Similarly, routine provision of a comprehensive array of individualized services has resulted in major decreases in TB cases in New York (Dorsinville, 1998).

The need to integrate patient and community perspectives in TB program structure has been illustrated through a comprehensive review of the social science literature (Porter, Ogden, & Pronyk, 1999) and through Jaramillo's work in less-developed countries (Jaramillo, 1998). For example, "free" TB medicine and care may be extremely expensive to the patient who must incur travel expenses and lost wages to attend the clinic (Jaramillo, 1998; Thomson & Myrdal, 1986; van der Werf, Dade, & van der Mark, 1990). Other economic studies have shown the high financial burden TB places on families (Murray, 1991; Needham, Godfrey-Faussett, & Foster, 1998; Wyss, Kilima, & Lorenz, 2001) and have shown the need for assessing patient costs and acceptability when designing TB programs (Heymann, Sell, & Brewer, 1998). From a policy-oriented perspective, Dievler and Pappas' (1999) research in Washington, DC, showed that racial and class tensions undermined planning processes, resulting in inappropriate and poorly implemented policies. In a comparative case study, Dievler (1997) found that New York, unlike Washington, DC, had community and political will supporting TB services and that plans were specific and implemented.

CURRENT TOOLS AND APPROACHES

Through the application of research to practice, advances have been made in understanding health cultures and the impact of health systems and have resulted in the development of new tools and approaches to improve the quality of patient care and service delivery. Adopting social science theories and methods, many health care practitioners have applied patient-centered treatment models. These models address barriers to adherence by using a wide range of interventions, including monetary and social incentives, patient education, cultural competency training, supervised therapy, community health worker involvement, and comprehensive services (Banerjee et

al., 2000; CDC, 1994; Dick & Lombard, 1997; Farmer et al., 1991; Malotte, Hollingshead, & Rhodes, 1999; Morisky et al., 1990; Pozsik, 1989; Tulsy et al., 2000; Tulsy, White, Young, Meakin, & Moss, 1999). Few of these interventions, however, have been tested using controlled experimental design studies or in diverse cultural settings.

In the area of communication, anthropologists have developed a number of practical tools to enhance the quality of patient-provider interactions. The interview tool developed by Carey et al. (1997) for assessing cultural beliefs and attitudes has helped programs better understand their diverse patient populations. Along the same lines, Qureshi (1994) pioneered the discipline of "transcultural medicine" in the United Kingdom in an effort to avoid problems stemming from providers' ignorance of patients' health cultures and attitudes. Other TB programs have developed manuals to heighten understanding of the cross-cultural issues pertinent to TB (Kalihi-Palama Health Center, 1997; Melendez & Smith, 2000). In addition, social scientists have developed guides and recommendations to facilitate communication between patients and providers and improve service delivery, many of which have been integrated into the CDC Self-Study Modules on Tuberculosis (CDC, 1995a).

Numerous theoretical models and methodologies have been developed to better understand individual and interpersonal health behavior and perspectives on organizational and community interventions (Glanz, Lewis, & Rimer, 1997). One of the earliest models developed to explain health behavior was the Health Belief Model, originally designed to understand individuals' willingness to seek screening for TB (Becker, 1974). Under this model, it is believed that people need to perceive themselves as susceptible to TB and able to personally benefit from early detection before seeking preventive health screening (Glanz et al., 1997). Researchers have applied this model, as well as others, in the design of educational materials and appropriate interventions (Ailinger & Dear, 1997; Kitazawa, 1995; Kleinman, 1980, 1989; Rubel, 1993; Shrestha-Kuwahara et al., 2002; West, 1993).

Methodologies traditionally used in anthropological research, such as participant observation and discourse analysis, yield rich information regarding health beliefs and behaviors (Ndeti, 1972). Recently, social network methods, which systematically measure the complex interconnections between and among persons, have been theorized (CDC, 2001; Chin et al., 2000; Klovdahl, 1985; Klovdahl et al., 2001; MacQueen, 2000) and

adopted to improve the effectiveness of TB contact investigations (Fitzpatrick et al., 2001).

To facilitate and enhance analysis of data collected from qualitative methods, social scientists have developed new research methods and computer software programs, including CDC EZ-text and AnSWR (AnSWR, 2001; Carey, Morgan, & Oxtoby, 1996; Carey, Wenzel, Reilly, Sheridan, & Steinberg, 1998; Carey et al., 1997; CDC, 2001; MacQueen, McLellan, Kay, & Milstein, 1998). Furthermore, to assist decision-makers in integrating social science research into policy planning, Ogden (2000) has defined a framework that can be used at the national and local levels. Recent exploration of TB and gender issues has also contributed to the development of models that enable decision-makers to integrate social and cultural factors into policy planning (Uplekar, Rangan, Weiss, Ogden, & Borgdorff, 2001).

FUTURE DIRECTIONS FOR SOCIAL AND CULTURAL RESEARCH

As this entry has shown, anthropology and other social sciences have brought new perspectives on an ancient disease. While notable contributions have undoubtedly been made, this review has identified wide gaps regarding the theoretical issues pertinent to TB control. Recognizing the broader sociocultural dimensions of TB, many social scientists stress the need to examine the structural barriers hindering the development and sustainability of interventions (Manderson, 1998). Critics of the purely cognitive or cultural explanations point out that many ethnographic studies have demonstrated that predictors of care-seeking, compliance, and treatment outcomes are fundamentally economic and structural in nature (Barnhoorn & Adriaanse, 1992; Farmer, 1997; Mata, 1985; Sumartojo, 1993).

Anthropological methods can be important tools to identify social forces that impact TB transmission and hinder equitable access to care (Grange, Gandy, Farmer, & Zumla, 2001; Porter et al., 1999). Ethnographic research, such as that conducted by Grygier (1994) on the TB epidemic among the Inuit people in Canada, can help to recapture the human perspective of a disease epidemic such as TB. There is also a continuing need for ethnographic studies of attitudes toward TB at all levels of society, including the perceptions, priorities, and motivating factors at governmental and international levels (Grange & Festenstein, 1993). Additionally, social science research can contribute to a better understanding of the health care envi-

ronment and how operational and infrastructural factors impact TB control efforts (Brudney & Dobkin, 1991; Farmer et al., 1991; Sumartojo, 1993).

This review has pointed out the dearth of evidence that anthropologists have investigated in developing, implementing, evaluating, and disseminating new interventions to improve the effectiveness of TB control programs. Anthropologists and other social scientists can play a critical role by engaging in systematic, theory-based, multidisciplinary research using scientifically rigorous experimental and quasi-experimental designs to improve specific aspects of TB control programs. With a vast array of theoretical models and frameworks, social scientists should play a greater role in exploring new, theoretically grounded yet pragmatic ways of assisting public health personnel in using social science for strengthening TB prevention and control policies and practices. These changes would be consistent with the expanding roles of other social and behavioral science disciplines in public health over the past two decades (Snider & Satcher, 1997).

TB control experts can learn from their counterparts' experiences battling the AIDS epidemic. HIV/AIDS researchers have advanced the understanding of the relationship between social structural factors and disease and have explored the dynamics of the epidemic in terms of social vulnerability rather than of individual risk (Mann & Tarranto, 1996; Porter et al., 1999). They have also developed frameworks to better understand the impact of structural factors on patient outcomes (Blankenship, Bray, & Merson, 2000; Sumartojo, 2000). These lessons are equally applicable to the dynamics of TB. Social scientists stress the need to look beyond the current biomedical model of TB control toward a multidisciplinary research framework. Jaramillo, for example, has proposed moving toward a new paradigm of epidemiology that is informed by the debate between "individual agency" and "structure" in explaining patterns of disease. This model is more inclusive of three different levels of causality: biological, health-behavioral, and socioeconomic. This more integrated view of causality asserts that control measures need to come from different levels of organization, and, thus, implies a more comprehensive agenda for research and control activities (Jaramillo, 1999b).

The World Health Organisation (WHO) and the Institute of Medicine (IOM) have emphasized a call made at an earlier meeting (CDC, 1995b) for more social science research in TB control (IOM, 2000). The IOM report articulates the need to understand the determinants of the behavior of providers, pa-

tients, and systems and to improve methods for predicting and monitoring adherence to therapy. Other areas needing research are the ethical and human rights issues around the use of directly observed therapy, legal detention of patients, and participation in drug trials.

TB is a serious global public health problem and, unless radical changes occur in TB control efforts, overall prevalence will likely increase (Porter et al., 1999). In most of the developing world, poverty, malnutrition, and overcrowding challenge TB control efforts. In industrialized nations, the risks associated with TB—social marginalization, malnutrition, substance use, unemployment, and congregate living—continue to flourish. Backed by renewed commitment to social and behavioral research, social scientists clearly have a critical role to play in the effort to control and eventually eliminate TB.

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