

Gender
and Health
Research
Series

Gender in
Tuberculosis
Research



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Gender in Tuberculosis Research



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Preface

The WHO Gender and Health Research Series has been developed by the Department of Gender, Women and Health (GWH), with assistance from other WHO departments, in order to address some of the main issues involved in integrating gender considerations into health research. This publication on Gender in Tuberculosis Research constitutes one of the booklets in this series.

Sex and gender are both important determinants of health. Biological sex and socially-constructed gender interact to produce differential risks and vulnerability to ill health, and differences in health-seeking behaviour and health outcomes for women and men. Despite widespread recognition of these differences, health research has hitherto, more often than not, failed to address both sex and gender adequately.

In applied health research, including the social sciences, the problem has traditionally been viewed as one of rendering and interpreting sex differentials in data analysis and exploring the implications for policies and programmes. However, examining the gender dimensions of a health issue involves much more than this; it requires unravelling how gender roles and norms, differences in access to resources and power, and gender-based discrimination influence male and female health and well-being.

Integrating gender considerations in health research contributes to better science and more focused

research, and, consequently, to more effective and efficient health policies and programmes. With these ambitions in mind, the objectives of the gender and research series are to:

- raise awareness of the need to integrate gender in health research;
- provide practical guidance on how to do this; and
- identify policies and mechanisms that can contribute to engendering health research.

The series is aimed at researchers, research coordinators, managers of research institutions, and research funding agencies. It comprises booklets covering both a general introduction to “engendering” the research process as well as topic-specific issues such as lung cancer, tuberculosis and mental health. The research series will be extended to other health topics in time.

Each booklet will review the particular health issue from a gender perspective, identify best practices in addressing gender in research and the gaps in gendered research, and make recommendations to address those gaps.

Research clarifying the role of gender in tuberculosis control is concerned with specific sociocultural, socioeconomic, and structural barriers affecting men and women, as distinct from sex-based differences in the biological vulnerability affecting epidemiology and pathophysiology of pulmonary TB. This review examines various studies in the literature of health and social science research and recent innovative studies undertaken by WHO/TDR.

The findings indicate that women progress from infection to active TB faster than men do, but the reported incidence of pulmonary TB among women is nearly always lower than for men. It remains unclear whether

and to what extent these differences are a true reflection of disease incidence or an indication of health system failures to detect and report female cases. We also know that for unexplained reasons, women are more likely than men to adhere to treatment and to complete a full course. Research on gender and TB now needs to focus on ways of enhancing the effectiveness of case finding for women, preventing treatment default, and identifying operationally precise reasons for default among men and women. The stepwise gender-specific barrier framework guiding this review helps to ensure a practical focus for such research.

List of abbreviations

BRAC	Bangladesh Rural Advancement Committee
CIDEIM	Centro Internacional de Entrenamiento e Investigaciones Médicas
DANTB	Danida Assisted Revised National Tuberculosis Control Programme
DOTS	Directly observed treatment, short course*
HIV/AIDS	Human immunodeficiency virus/acquired immunodeficiency syndrome
IEC	Information, education and communication
ILO	International Labour Organization
NGO	Nongovernmental organization
NTPs	National tuberculosis programmes
PHC	Primary Health Care
TB	Tuberculosis
TDR	WHO Special Programme for Research and Training in Tropical Diseases
UNDP	United Nations Development Programme

* DOTS is the internationally-recommended TB control strategy which combines five elements: political commitment, microscopy services, drug supplies, surveillance and monitoring systems, and use of highly efficacious regimes with direct observation of treatment.

1. Introduction

Tuberculosis (TB) remains a major cause of infectious disease mortality worldwide, responsible for an estimated 1.6 million deaths annually or 2.8% of global mortality. In 2002, nearly twice as many men died from tuberculosis as women (1 055 000 deaths or 3.5% of all deaths in men and 550 000 deaths or 2.0% of all deaths in women). Even so, more women died of TB than from all maternal conditions (1.9% of all female deaths) and breast cancer (1.8% of all female deaths) (WHO, 2003a). Both women and men with TB are likely to be in their most productive years, that is, in the age range 15-44 years old (Stop TB, 2003). At this age men are typically responsible for earning and supporting their families, whereas women as workers, mothers and caregivers usually have families and children who suffer additionally from their illness and death.

Notification rates of pulmonary TB for males are nearly always higher than that for females (Borgdorff et al., 2000). However, the true magnitude of male excess for pulmonary TB is difficult to quantify, partly because case detection in most prevalence surveys is by sputum microscopy, which appears to be less sensitive in detecting TB in women than it is in men. Questions and debate persist about whether the male preponderance for TB stems more from sex (i.e. biological) differences or more from sociocultural or gender-based differences (Thorson et al., 2000; Borgdorff & Maher, 2001; Thorson & Long, 2001). The distinction between

"sex" and "gender" as terms for describing differences between men and women, and role of gender as a determinant of health status, are explained in more detail in Box 1 (next page).

Rates of TB are generally high across the countries of south-east Asia, where TB accounts for between 4.3% and 7.2% of total deaths (WHO, 2003a). Demographic questions here are especially concerned with a disproportionately high female mortality from TB relative to other world regions (Sen, 2003). Persisting patterns of social discrimination against women and unfulfilled social responsibilities of men underscore diverse and complex relationships between cultural values, social practices, and gender-related health and social policy. Widespread stigma targeting people with TB, especially women, further complicates the interactions between this disease and normative gender roles in this part of the world (Hudelson, 1996; Balasubramanian et al., 2004). Almost everywhere, however, interactions between society, culture and TB control raise important questions about the role of gender and discrimination in all aspects of the disease, from case finding to diagnosis, treatment and eventual outcome. Public health professionals concerned with TB have long emphasized the role of poverty, living conditions and non-specific determinants of health. In 1921, Allen Krause, director of the TB laboratories at Johns Hopkins noted:

Sex and Gender

Sex is the term used to distinguish men and women on the basis of their biological characteristics. **Gender** on the other hand refers to those distinguishing features that are socially constructed. Gender influences the control men and women have over the determinants of their health, for example, their economic position and social status, and their access to resources. Gender configures both the material and symbolic positions that men and women occupy in the social hierarchy, and shapes the experiences that condition their lives. Gender is a powerful social determinant of health that interacts with other variables such as age, family structure, income, education and social support, and with a variety of behavioural factors.

What then do we mean by gender-sensitive research and why is it considered to be so important? Research that fulfils this objective includes considerations of gender at all levels of the research process, from commissioning and study design through to dissemination of the results. Moreover, sex and gender must be identified as key variables, in all measures, reported separately and the differences discussed (Doyal, 2002).

Health research that is gender sensitive is necessary because sex and gender rank among the key factors, alongside socioeconomic status, ethnicity and age, that determine the health of women and men. Sex and gender affect biological vulnerability, exposure to health risks, experiences of disease and disability, and access to medical care and public health services. Research which is gender in-sensitive may result in study design which is unable to differentiate between women and men in the identification of key findings and their policy implications. Gender-sensitive research, on the other hand, is more likely to lead to improved outcomes in treatment and preventative interventions (Doyal, 2002).

The role of gender in public health is now widely acknowledged and is a core component of many health programmes, both international and national. Sex and gender as determinants of health, and as components of a conceptual framework for health research, are discussed in more detail in an accompanying booklet in this WHO Gender and Health Research Series.

“The solution of the tuberculosis problem is partly dependant on the removal of other evils and inequalities which constitute, no doubt, a more fundamental problem than does tuberculosis itself.” (quoted in Farmer, 1999).

Various extraordinary social stressors, such as war, migration, imprisonment and forced labour may also potentiate the spread of TB in affected countries and communities, with gender-specific effects on both men and women.

This review is concerned with the interrelated aspects of gender and control of pulmonary TB, and has been prepared as one of a series of disease-specific studies of health and gender. Following a brief overview of the broad categories of scientific inquiry that can be used to study gender and TB, the main part of the document reviews what is currently known about gender influences on the occurrence of TB, help-seeking behav-

iour, diagnosis and treatment initiation, treatment adherence, and disease outcome (sections 3-7). For each of these main areas of study, specific recommendations for future research are given. Preliminary results from the recently completed four-country study of gender and TB, conducted under the auspices of the WHO Special Programme for Research and Training in Tropical Diseases (TDR), are presented in a separate section (section 8). By integrating the methodologies of the social sciences, basic epidemiology and cultural epidemiology, these studies have provided some valuable insights into the way that gender shapes the experience of TB. Finally, a number of representative policy documents are analysed with a view to assessing what progress has been achieved to date in terms of integrating gender into TB control programmes at both the national and global level (section 9).

2. Tools for the study of gender and TB

Ethnography and cultural epidemiology

Successful TB control requires identification of people with signs and symptoms of TB, confirmation of diagnosis, efficacious treatment regimens and sustained case holding. Consequently, WHO has developed its TB control programme, DOTS (directly observed treatment, short course) well beyond the hallmark of direct observation. DOTS combines five key elements: political commitment, diagnosis with sputum microscopy of symptomatic clinic patients, standardized and supervised short-course chemotherapy that includes direct observation, regular drug supply, and a standardized recording and reporting system for documentation of treatment for both individual patients and overall programme performance.

The determinants of illness behaviour, which ultimately determines the success of a TB control programme, are, however, rooted in social and cultural contexts. Risky and help-seeking behaviours are influenced not only by the accessibility of services but also by personal experiences and meanings of illness, as well as by sociocultural responses. The latter may either encourage (e.g. by promoting the importance of health care and treatment) or restrict (e.g. by instilling shame, humiliation and fear of disclosure among affected persons) the effective use of health services. Social environments are a strong influence on health-seeking behaviour,

adherence to treatment, and ultimately, illness outcome.

Ethnographic study has proved to be a valuable tool for identifying the sociocultural features of TB and their impact on TB control. Ethnographic study techniques provide: a) categories of local experience, meaning and behaviour with reference to symptoms and the impact of illness on people's lives; b) ideas about the cause and appropriate ways of dealing with illness; and c) strategies to deal with symptoms. Local knowledge of illness not only helps to explain the impact of TB on individuals, families and communities, but also contributes to the formulation of effective control strategies.

Local normative differences affect the ways that men and women with TB experience and explain their condition, and what they do about it. Ethnographic studies in Vietnam, for example, have identified several different types of TB (Long et al., 1999a). Among women, TB was frequently attributed to emotional and social causes, such as worrying, an unhappy life, and poverty; men, on the other hand, identified hard manual labour, or questionable social activities (e.g. going out with friends to eat, drink and smoke) as causes of TB. Individuals' perceptions of risk can play a decisive role when it comes to seeking help for TB. For instance, women may be more likely to minimize or ignore symptoms of TB if they

believe that men are more likely to suffer from TB; furthermore if they consider themselves unlikely to be at risk, this might discourage those with TB from seeking treatment. Similarly, health professionals may also be less aggressive in considering and diagnosing TB in women with respiratory symptoms.

Local sociocultural contexts can also influence other aspects of TB-related experience and meaning. In Kenya and Pakistan, doubts about whether TB can be completely cured were commonly observed (Liefvooghe et al., 1995; 1997). Notions about the futility of treatment may deter patients from seeking care, or undermine advocacy for improved resources and access to TB services. In Pakistani communities, social costs are especially high for individuals identified with TB; women in particular are fearful of contracting TB because it decreases a single woman's marriage prospects and increases the married women's vulnerability to divorce. Such stressors discourage women from acknowledging symptoms and seeking appropriate care.

Anthropological studies generally focus on the community as the unit of study, and thus generate useful information about the practical impact of culture and gender on TB in affected communities as a whole. Variation among residents within communities is more difficult to study with anthropological methods. The strength of such methods lies in their ability to suggest a causal web of interactions between culture, gender and illness; such hypotheses require further research to test their validity. Anthropological studies also raise

questions about the relative impact of local experience, meaning and behaviour. Cultural epidemiological research addresses the questions raised by anthropological studies and examines the relative role of particular ethnographic findings (Weiss, 2001).

A framework for the study of gender and TB

To be effective public health models for TB control need to take account of the effects of poverty, inequity and other social, educational, political and economic factors that together influence health and illness behaviour. Each of these factors, all of which are mediated by gender, affects various aspects of disease control.

Uplekar and colleagues (2001) have formulated a stepwise attrition model for the purpose of analysing the impact of gender on TB control (see Figure 1). Their model suggests a research agenda for addressing questions about the role of gender at various points in the sequence of events from initial awareness of symptoms to illness outcome. Seven steps are defined:

- (1) awareness of symptoms,
- (2) appropriate help seeking,
- (3) interaction with health services,
- (4) diagnosis,
- (5) initiation of treatment,
- (6) adherence to treatment,
- (7) positive outcome.

The model relies on a framework to identify a series of barriers that may lead to gender disparities at each of the above steps and thus compromise the effectiveness of TB control programmes. In order to identify these

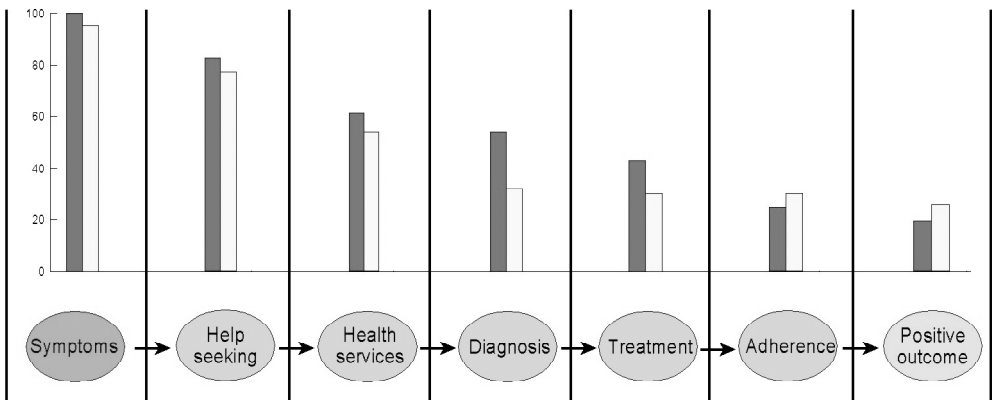
barriers at each step in the course of effective TB control, the framework poses questions about "self-image, status in the family and society, access to resources, manifestation and expression of symptoms and stigma associated with TB" (Uplekar et al., 2001). The framework recognizes that gender not only influences the behaviour of TB-affected persons in the community, but also influences provider bias, the effectiveness of sputum examination, and the level of clinical suspicion required to make a diagnosis of TB. Consequently, the model identifies specific research needs to determine whether and how various barriers affect the gender balance of TB.

studies, consider gender as a major determinant of disease recognition, health-seeking, treatment and outcome, alongside contextual factors such as socioeconomic status and cultural values. The gender-specific barrier framework outlined above, however, is particularly useful because it helps researchers and policy-makers to examine systematically the critical features of TB control. This review has been shaped to a large extent by this framework, but consolidates some of its elements that are not amenable for individual study. The modified gender-specific barrier framework, on which the main part of this review is based, thus covers the following topics:

Although other investigators have analysed various aspects of gender, none has done so within such a comprehensive framework that seeks to cover the full range of activities required for planning TB control. For example, Johansson and colleagues (2000), in common with several other

1. Occurrence and basic epidemiology of TB.
2. Help seeking and access to health services.
3. Diagnosis and initiating treatment.
4. Treatment adherence.
5. Treatment outcome.

Figure 1. Gender differentials for clarification and study at each step in the course of effective TB control



Stepwise barriers and tentative indication of the number of men and women reaching each step in the recognition, treatment, and cure of TB.

■ Men □ Women

(Source: Uplekar et al., 2001)

3. Occurrence and basic epidemiology of TB

Although an estimated one third of the world's population is infected with TB, only 5-10% of those without HIV/AIDS will proceed from infection to active pulmonary TB (active cases are identified by a positive sputum smear). A compromised immune system increases that percentage. Among the major world regions, south and south-east Asia have the largest incidence of infectious cases and the most deaths, although the highest per capita incidence rates and mortality occur in sub-Saharan Africa (WHO, 2003a).

Sex-specific incidence and prevalence data are the starting point for the analysis of sex and gender differences in the occurrence of any disease, and TB is no exception. According to WHO data on case notifications of sputum-positive TB, 70% more men than women have active TB (Diwan & Thorson, 1999; Uplekar et al., 2001). The observed male excess in notifications may be because there are fewer women in the population with active TB, but it could be a consequence of the fact that fewer women with TB present for treatment, or that, among those women with TB who come to a clinic, fewer are identified as smear positive.

Recently reported WHO data reveal that the male:female ratio for case notifications of smear-positive cases in DOTS areas of the WHO regions for all ages range from 1.35:1 in Africa to 2.16:1 in Europe (WHO, 2004).

Ratios for specific age groups in each of the WHO regions are given in Table 1 (page 12). Analysis of gender differences is inhibited by the fact that data for DOTS detection rates and DOTS treatment success are not disaggregated by sex in the annual WHO reports on global tuberculosis control.

Research findings uniformly suggest that prior to adolescence there is little difference between men and women in terms of their TB infection rates. From approximately age 15 onwards, however, when both biological and social changes associated with adolescence differentiate the sexes more markedly, men begin to overtake women in their rates of infection. Moreover, as they grow older, men have a higher likelihood of progressing from infection to disease (Long, 2000). Men are typically more widely exposed to other people with infectious TB, as a consequence of their greater social interaction outside the home. Other behavioural differences between men and women that may contribute to higher risk for infection among men and progression from infection to active TB from a weakened immune system include smoking, alcoholism, migration and in some cases, imprisonment.

Several studies have attributed the lower infection rates in women to less social interaction outside the home, something that is characteristic of adolescent females in many societies (Fair, Islam & Chowdhury, 1997;

Table 1

Male:female ratio of smear-positive TB notifications, by age group and WHO region

WHO Region	Age group (years)							Total
	0-14	15-24	25-34	35-44	45-54	55-64	65+	
Africa	0.84	0.94	1.28	1.73	1.95	1.87	2.04	1.35
Americas	0.84	1.22	1.39	1.65	1.84	1.87	1.58	1.49
South-East Asia	0.60	1.33	1.66	2.39	2.90	3.08	3.15	2.03
Europe	0.78	1.34	1.81	2.97	4.27	2.97	1.22	2.16
Eastern Mediterranean	0.92	1.25	1.51	1.49	1.46	1.36	1.40	1.37
Western Pacific	0.78	1.40	1.78	2.27	2.54	2.51	2.48	2.09
Total	0.78	1.18	1.50	2.06	2.45	2.48	2.36	1.74

Source: WHO (2004). *Global tuberculosis control: surveillance, planning, financing. WHO report 2004*. Geneva, World Health Organization (computed from data presented in Annex 2).

Dolin, 1998). Evidence from India, for instance, shows that working women with a wider pattern of social interactions, particularly rural women and women commuting between rural and urban areas, are more vulnerable to infection and the disease (Ogden, Rangan & Lewin, 1999). The argument is not entirely satisfactory, however, inasmuch as transmission patterns suggest that TB spreads readily indoors, and the risk of infection is promoted by prolonged close contact. Caring for old or sick people, tasks that traditionally are a feature of female gender roles in many societies, would, for example, possibly increase women's risk of infection through close contact more than a man's (Diwan & Thorson, 1999).

A number of studies have shown that the rate of progression from infection to disease is significantly higher for women of reproductive age than for men of the same age. There is also some evidence to suggest that after adolescence until age 25-30 years, women with TB have a higher case:fatality ratio than men in the same age group with TB (Connolly & Nunn, 1996; Holmes et al., 1998). A prospective cohort study in Bangladesh, for example, reported that women aged 10-44 years of age had a 130% higher risk of progressing from infection to clinical disease than men in the same age group (Dolin, 1998). Some questions remain about the validity of these findings; more cases during child-bearing years may be a reflection of better detection rather than higher rates, as women attend clinics more frequently for pre- and postnatal care, and for health care needs of their young children (Long, 2000).

The reasons for the higher rates of progression from infection to disease and higher mortality in women remain unclear (Dolin, 1998). Sex differences and physiological changes occurring in pregnancy are unlikely to be the only factors. It is possible that gender inequalities governing various risk factors, such as poor nutrition, may make women at this stage of life more vulnerable to progression from infection to active pulmonary TB. Differences in treatment compliance and sociocultural barriers to help-seeking have also been proposed as possible explanations (Dolin, 1998). Gendered differences in help-seeking behaviour mean that women typically delay seeking care and hence treatment, thereby increasing their risk of TB mortality (i.e. the so-called gender-specific barrier hypothesis).

Historical evidence from Europe and North America suggests that during the mid-1900s, when the prevalence of active TB was high, women aged between 15 and 35 years had higher rates of active TB than men in the same age cohort (WHO, 2003b). These data support the theory that the apparent lower female incidence of active disease globally is less a reflection of biological differences in vulnerability but rather a consequence of gross undercounting of active female cases, perhaps because clinicians are less attentive to diagnosing TB in women. If true, these data also lend weight to the gender-specific barrier hypothesis mentioned above which suggests that later help-seeking in women means that they have more advanced TB when they eventually do present for treatment, and thus higher case-fatality rates. Accordingly, a late presentation has been attributed to sociocultural per-

ceptions of TB that influence awareness of the seriousness of, and response to, symptoms. If TB is more likely to present in women in gender-specific patterns that sociocultural perceptions do not associate with TB, then the significance of symptoms are more likely to be minimized, which in turn further reduces opportunities for diagnosis (Ogden, Rangan & Lewin, 1999).

Research conducted in Kenya by Liefoghe and colleagues (1997) revealed that TB patients only sought treatment after they had additional symptoms beyond persistent cough. Elsewhere, many patients failed to identify TB or even to consider the possibility of TB from their symptoms, especially the less well educated, who were often women (HealthScope Tanzania, 2003). This results in a tendency among individuals to minimize the importance of their health problems and to discount or ignore the need for treatment. Ogden, Rangan & Lewin (1999) in their study in India found that patients with TB often found it difficult to differentiate symptoms of a serious condition from those of milder problems, such as a common cold. Consequently, many patients did not present to a health centre or clinic for treatment until they experienced haemoptysis. Hoa et al. (2003) found that Vietnamese men with prolonged cough had better knowledge of TB symptoms than did women, and that recognition of symptoms they associated with TB correlated with seeking hospital care.

Research has demonstrated that men and women do in fact experience and interpret symptoms of TB differently. According to a study carried out in Vietnam by Long, Diwan &

Winkvist (2002), women with TB report cough, sputum expectoration and haemoptysis less frequently than do men. If women present to health centres without these characteristic symptoms, clinicians may not consider TB as a diagnosis. Health-care providers need to be aware of the possibility that some female TB patients may present with symptoms that are atypical for men with TB. It is important to consider gender-specific illness experience and reporting styles, and to recognize that such differences may vary between settings and cultures.

Pandemic HIV infection and AIDS further complicate TB epidemiology and control. TB is the most significant and life-threatening opportunistic infection for HIV. In India, Myanmar, Nepal and Thailand between 56% and 80% of people with AIDS also have TB (WHO, 2003b); men have a higher coinfection rate than women. The situation is different, however, in sub-Saharan Africa, where women have higher rates of TB coinfection with HIV than men (WHO, 2003b).

The social response to TB may be affected by regional patterns of HIV/AIDS comorbidity. Several studies have shown that in areas where HIV prevalence is high, and where people are aware of frequent coinfections and the shared symptoms of HIV and TB (e.g. wasting), the stigma targeting people with TB is often greater because they are assumed to have HIV/AIDS also. Consequently, in an effort to avoid the stigma of HIV infection, patients may be deterred from seeking health care for their TB (HealthScope Tanzania, 2003). As women tend to be more vulnerable to the impact of social stigma, this can

represent an additional gender-related barrier to women's access to health services, diagnosis and timely treatment.

In some parts of the world, destabilisation and stress arising from national, social and economic transitions have impacted adversely on TB epidemiology and control. For instance, in the Russian Federation, the male:female ratio of smear-positive TB cases under DOTS is 3.78, which compares with an average for the whole of the WHO European Region of 2.16 (WHO,

2004). In the former Soviet republics, the resurgence in pulmonary TB during the past decade has been largely attributed to the fragmentation of health services and to socioeconomic upheavals. Social stressors associated with the transition have contributed to higher levels of unemployment, migration and alcoholism, and a decline in living standards. Such factors and others (e.g. high rates of incarceration) have fuelled the current TB and multidrug-resistant TB epidemic, particularly among Russian men (Coker, 2001; Shilova, 2001).

Box 2

Recommendations for future research: epidemiology of TB

- Greater programme monitoring and more focussed studies are needed to compare male and female rates of TB, and thereby to clarify the magnitude of differences in relation to both biological and sociocultural determinants. Such research needs to consider sociocultural differences, patterns of other disease morbidity and local TB control programme strategies.
- The study of the progression from infection to disease should not be limited to reproductive health issues; both biological factors and the gendered aspects of men's and women's lives that contribute to social stress and support should also be considered.
- Recognizing the importance of TB as an opportunistic infection for HIV/AIDS, research is needed to clarify the distinctive gender-based vulnerabilities of men and women with reference to particular risk factors and the social dynamics of coinfection with this disease.
- Efforts to destigmatize both HIV/AIDS and TB should identify the disease-specific, culture-specific and gender-specific basis of social disqualification with reference to asymptomatic HIV infection, symptomatic AIDS and pulmonary TB, clarifying the particular ways that each may lead to correctable misperceptions of risks and unwarranted social exclusion.

4. Help seeking and access to health services

Many of the sociocultural and socioeconomic factors that influence detection rates of TB also affect help-seeking behaviour in both men and women. Some studies support the premise that the relatively lower number of female cases of active TB may be a consequence of barriers to help-seeking affecting women more than they do men. In Nepal, for example, Cassels and colleagues (1982) reported that among those who presented to health centres voluntarily, only 28% of TB cases were female. However, this percentage rose to 46% among those detected through active case finding. Harper, Fryatt & White (1996) also demonstrated that active as opposed to passive case finding in Nepal identified more female TB patients. These findings indicate that Nepalese women with TB are undercounted in clinic-based data. The undercounting is likely to be a result of a combination of factors including social barriers (e.g. TB-related stigma), women's immobility, economic dependence on husbands or family, and lack of education and awareness of the significance of TB symptoms.

In a recent population-based study from Vietnam that screened household residents for TB, Thorson et al. (2004) showed that prevalence of smear-positive pulmonary TB was slightly higher among women than men (male:female ratio, 1:1.22). This is in contrast to TB programme data, which report a 2:1 ratio of male

cases. On the other hand, in Tamil Nadu, India, Balasubramanian and colleagues (2004) reported community prevalence rates of smear-positive TB that were higher for men than women (male:female ratio, 6.5:1); the male excess was reduced among TB clinic patients (male:female ratio, 2.7:1). The findings of this study imply that women with TB are more likely to access clinical services of primary health-care institutions than are men.

Several studies have identified a number of reasons for delayed help-seeking that are common to both men and women. These include:

- distrust or a lack of confidence in government health facilities combined with the inconvenience and high cost of accessing such services (owing to distance from, and cost of travel to the clinic, and time lost from work);
- social stigma and reluctance to disclose their condition to others;
- a failure to attribute symptoms to TB or to acknowledge the seriousness of symptoms and the need for treatment (Godfrey-Faussett et al., 2002).

Although women in the above Tamil Nadu study faced greater stigma and other barriers to accessing health services, they were in fact more likely than men to do so. Balasubramanian and colleagues

(2004) attribute this to the fact that women are better able to attend clinics during opening hours, and because they are more likely to visit health centres for immunizations and for advice regarding health problems of their children.

In other parts of the world, women tend to be more likely than men to ignore the first signs and symptoms of TB and thus delay seeking treatment. In the United Republic of Tanzania, the average delay before seeking care at a public TB facility is 8 weeks among female patients but 6 weeks for male patients (HealthScope Tanzania, 2003). A woman's role as the primary family caregiver, coupled with a lack of financial control within the household, typically means that a woman places the needs of her children and other family members above her own, thus delaying help seeking for her own health problems, or reserving scarce resources for the care of other family members instead. Some women may never seek care. The same is true for men who are the primary breadwinners in the household; for them seeking timely care may be difficult or impossible, and adhering to treatment in a DOTS programme may impose the risk of losing wages or becoming unemployed.

Several lines of evidence indicate that stigma plays a greater role in shaping women's experience of illness and help-seeking behaviour than men's. Being largely dependent on their husbands or families, women's concerns about the social impact of TB may include realistic fears of isolation, rejection from their family households and even divorce. Various factors are responsible for such concerns, in particular, misconceptions

about the risk and spread of TB. Godfrey-Faussett and coworkers (2002) reported that among a sample of Zambian men and women, 79% declared that they would not like to use the same eating utensils as a TB-positive relative who was currently undergoing treatment, 60% would not like to marry someone who previously had TB, and 49% had would refuse to sleep in the same bed as a spouse in treatment for TB. Generally speaking, women are more frequently targets for such biases than men. According to a study by Johansson et al. (2000), women in Vietnam fear stigma more than men, so much so that they would often opt to isolate themselves as protection from stigmatizing interactions. Men, on the other hand, were more likely to be concerned with the economic burden of TB and its impact on their ability to work and earning potential. In sum, it appears that both men and women may deny TB symptoms for fear of TB-related stigma, but for different reasons.

Interestingly, when TB patients do seek care, many do not go directly to public health clinics. Several studies have found that women in particular reach clinical treatment services through a more circuitous route, preferring to seek help first from traditional healers or private practitioners (Johansson et al., 2000, Thorson et al., 2000; Yamasaki-Nakagawa et al., 2001; Rajeswari et al., 2002; Sudha et al., 2003). In India, initial help-seeking from private practitioners is common; Rajeswari and colleagues (2002) found that 54% of patients first sought care from private practitioners whereas only 27% went first to government health facilities for help. A study carried out in rural and

urban districts in Pune, India, revealed that 60% of patients sought care outside of government facilities, and that among those who did seek care at government facilities, over two thirds also consulted non-allopathic healers (Uplekar & Rangan, 1996). Other studies have demonstrated similar patterns of help-seeking behaviour. In Nepal, Yamasaki-Nakagawa et al. (2001) reported that approximately half of all study subjects (men and women) first sought care from a private practitioner, and, furthermore, that more women had consulted such providers before they were diagnosed with TB. Nearly all patients in this study (94%) had ready access to traditional healers, i.e. they were reachable within 30 minutes. Government-run health facilities were less accessible to most people in that only 50% of those surveyed said that they could reach such services within 30 minutes. In a rural Pune district, India, it has been reported that many patients must travel 15 km or more to a health clinic for treatment (Morankar & Weiss, 2003).

Private health care providers do not necessarily prescribe the optimal treatment for TB, a problem that is well documented in Mumbai (Uplekar, 1995). They are also less likely to diagnose TB with sputum smears, depending rather more on less reliable X-ray techniques. As indicated above, women are more likely to consult diverse sources or "shop" for treatment, even when they do not delay seeking care longer than men. In addition, not only are women more likely than men to first consult private doctors, but they are also more likely to medicate themselves (Ogden, Rangan & Lewin, 1999; Thorson et al., 2000). The "shopping" for treatment

often delays diagnosis and the start of effective treatment. This is a problem not only for the patients themselves but also for the public at large, because more people are exposed to potentially infectious persons for a longer period of time. Focus group discussions in Vietnam have suggested that although men typically neglect health seeking for TB until symptoms become severe, they are then more likely to seek care at a government hospital (Thorson & Diwan, 2001).

Somewhat paradoxically, poverty may compel people with TB to seek care in the private sector instead of at DOTS programme clinics. Although TB medicines in the public sector are provided without charge, hidden costs (such as the cost of travel) may put these services beyond the reach of many (Johansson et al., 2000). In Nepal, women first sought care from private practitioners, even when they were aware that free treatment was available at the government health clinics, largely because household responsibilities discouraged them from travelling the longer distances to government clinics (Yamasaki-Nakagawa et al., 2001). Some national guidelines require patients to stay in hospital for the first two months of treatment, which can impose a serious economic burden on both patients and their families if they cannot work during that period (Johansson et al., 2000).

In addition to their proximity, other factors may contribute to the appeal of private practitioners. Local private doctors and traditional healers are often well known and trusted, and perceived as more responsive to patients' needs. Patient-centred services, convenient hours and advice

Box 3

Recommendations for research: access to treatment

- More research is needed on gender-specific barriers to health care, in particular those relating to symptomatology, lifestyle and social roles. Findings should be used to guide information, education and communication (IEC) interventions that are capable of surmounting patient-specific and health-system barriers to appropriate help-seeking for TB.
- The utility of active case finding should be investigated to complement the passive case finding that typifies most DOTS programmes, so that such data may quantify more accurately the true magnitude of the treatment gap.
- As poor women tend to prioritize the needs of other family members over their own, especially their children's, the feasibility and usefulness of integrating TB diagnostic services with maternal and child health care, Integrated Management of Childhood Illnesses services, and/or Safe Motherhood initiatives should be explored.
- The feasibility and possible benefits of restructuring clinic operations (e.g. adjusting the opening hours) should be investigated. The impact of minimizing inconvenience for patients with other ongoing responsibilities should form part of such investigations.
- The impact of reducing the emotional burden and of improving clinic attendance of patients by enhancing social support skills and priorities for community advocacy among health-care personnel, in a manner sensitive to identified gender-specific patient needs, should be studied.
- In connection with widely-recognized priorities for improving the quality of TB care, the value of including a gender component in case management training for the distinctive contexts of both public health services and private practice should be explored.

that goes beyond antibiotics (e.g. counselling on lifestyle and diet) offered by private practitioners are likely to be highly valued by patients (Ogden, Rangan & Lewin, 1999).

Sensitivity to social concerns and the emotional impact of TB on women may also determine whether or not particular providers are acceptable (Uplekar et al., 1999).

5. Diagnosis and initiating treatment

It is useful to distinguish "patient delay", a term used to refer to the time from onset of symptoms to first contact with a health-care provider, from "provider delay", which refers to the time from first contact with a health-care provider to diagnosis. Several studies have shown that even in settings where more women than men present for care, they experience longer provider delays (Long et al., 1999b; Needham et al., 2001). In Vietnam, according to a study carried out by Long and colleagues (1999b) provider delay averaged 3.8 weeks for men but 5.4 weeks for women. In an attempt to determine the reasons for this, Thorson and Johansson (2004) analysed physicians' perceptions of the longer provider delay for female TB patients. Among the reasons given, physician respondents mentioned the behaviour of female patients, explaining that even after a consultation requesting sputum for diagnostic testing, female patients often returned home for approval from their family and neighbours before providing a sputum sample. Men, on the other hand, were more likely to demand a comprehensive diagnostic evaluation from their doctors (Thorson & Johansson, 2004). Delayed diagnosis compromises the health of women patients, and it also potentiates the spread of infection.

An earlier population-based study in Vietnam found that sputum testing was prescribed for men with symptoms of prolonged cough significantly more often than it was for women

(Thorson et al., 2000). The WHO now recommends that all patients who present at health centres with a prolonged cough (i.e. of more than three weeks duration) should be tested for pulmonary TB through direct microscopic examination of sputum. However, some evidence suggests that such screening procedures may be less sensitive for detecting TB in female patients than in men (WHO, 2002). Low sputum positivity among women with TB may result from women's inability to produce sputum of the required quantity and quality for testing. False negative results are thus more common in women than in men. It is therefore critical that health-care providers recognize that women with TB are more likely to present for treatment without normative symptoms and without positive microscopy (WHO, 2002).

Women may still experience longer diagnostic delays even when they present with typical symptoms. In Vietnam, Thorson et al. (2000) reported that in settings where the prevalence of prolonged cough is similar for men and women (1.5% for men, 1.3% for women), women were less frequently tested by sputum smear microscopy than men (36% of men versus 14% of women in study sample). Observations in Bangladesh (Begum et al., 2001) and India (Uplekar et al., 1999) also indicate that fewer women undergo sputum microscopy when they seek treatment for comparable respiratory symptoms. Whereas two out of every

three men with chest symptoms were tested for TB in a clinic in Gujarat, India, only one out of every three women with similar symptoms underwent sputum examination (Uplekar et al., 1999).

Several studies have explored the possible reasons for the observed differences in speed and probability of diagnosis. One possible explanation offered is that women may be too embarrassed or ashamed to produce a sputum sample at the health centre because it is socially discomfiting for them to cough vociferously in public (Uplekar et al., 1999; Begum et al., 2001; DANTB, 2002). Alternatively, some women may be physically unable to produce quality sputum (Murthy et al., 2000). In order to overcome such physiological limitations, Murthy and colleagues (2000) used a bronchodilator, oral salbutamol, to facilitate sputum production for clinic patients; patients who had difficulty producing sputum for microscopy were given a second dose. Use of oral salbutamol was found to increase the rate of positive diagnostic testing for TB overall (of the 636 identified sputum-positive cases, 206 required salbutamol). In the sample of 2 099 patients who

presented with chest symptoms roughly equal numbers of men and women tested positive for TB. The enhanced diagnostic sensitivity was most notable for women, whose rates of positivity nearly doubled. Experience elsewhere, reported by the Tuberculosis Research Centre (2003) in Chennai, found that use of the bronchodilator failed to improve diagnostic sensitivity.

There are a range of factors, both general and gender-specific, that act to delay the start of treatment even after a correct diagnosis for TB; these include insufficiently staffed and poorly supplied clinics, difficulty in reaching a clinic due to high transport costs, and competing responsibilities and social obligations. The latter are likely to be a particular problem for women with TB; in some settings it may be difficult for them to get to the clinic to receive their medicines. In addition, health-care providers may deny proper treatment to certain patients (Singh et al., 2002). Data from two DOTS clinics in New Delhi, India, revealed that more than half of the patients were denied DOTS therapy, the majority of whom were very poor and/or socially marginalized (Singh et al., 2002).

Box 4

Recommendations for research: diagnosis and treatment

- There is a continued need to study clinical presentations of symptoms, patterns of illness experience and the perceived causes of symptoms in order to distinguish gender-specific from atypical presentations of TB.
- Further research is also needed to determine the reasons for provider delay in diagnosis, especially in the case of women, with a view to improving the diagnosis of TB generally and minimizing the gender differentials in diagnosis through training and supervision of health-care personnel.
- Further study of the efficacy of bronchodilators, such as oral salbutamol, for improving the quality of sputum for microscopy is needed. Such innovations for enhancing the sensitivity of diagnosis require further consideration and study to ensure the effectiveness of sputum examination in the context of DOTS programmes. The impact of structural adjustments in the organization of clinic operations and behaviour adjustments in patient provider interactions should also be studied.

6. Treatment adherence

Treatment adherence is a critical determinant of successful TB control; poor adherence may result in both treatment failure and development of resistance to TB medicines. Analysis of gender differentials has indicated that women who are diagnosed and begin treatment for TB are more likely to adhere to treatment for a full course than are men (Chan-Yeung et al., 2002). They are also more likely to have a positive treatment outcome (Bernatas et al., 2003). Male:female differences in treatment adherence are thought to be a reflection of the commitment of the subset of tenacious women who overcome barriers to seeking health care and receive a diagnosis. Implicitly referring to a barrier model, Uplekar et al. (1999) have suggested that the antagonistic socio-cultural and socioeconomic barriers women face prior to treatment act to filter out those who would potentially default from treatment. However, the higher utilization of clinics by women in some settings counters the argument that greater motivation arises from overcoming barriers (Balasubramanian et al., 2004). Alternatively then, one might ask whether the greater vulnerability of women to stigma may motivate those with confidence in the value of treatment to stick with it, and in so doing remove the target of their stigma.

Although stigma might sometimes act as a motivator, it often causes problems for treatment adherence. Women's sensitivity to social stigma, in particular, has given cause for concern in DOTS programmes, which

have become the cornerstone of TB control. The policy is based on the premise that observing patients taking their medicines in a health centre or at home improves treatment adherence and outcome. Direct observation of treatment, however, can make it much harder to conceal one's illness from the community. Morankar and Weiss (2003) reported that for 70% of women in Maharashtra, India, consuming medicines in the presence of a health-care practitioner was unacceptable. If they must take their medicines under direct observation, these women preferred to do so under the supervision of a female nurse. These findings support those of an earlier study, by Balasubramanian et al. (2000), which also indicate that women are less likely to accept DOT than men because of concerns about social stigma (61% compared with 76%, $P = 0.06$), and that failure to receive DOT accounted for most of the treatment failures. The authors went on to suggest that, as an alternative, other persons, such as trained midwives, community volunteers, shopkeepers, members of nongovernmental organizations (NGOs), religious leaders, students, cured patients and family members, might be able to provide DOT more effectively outside clinic settings.

Whereas stigma is typically cited by women as one of the primary reasons for their treatment dropout, narrative accounts of men are more likely to emphasize economic concerns as the cause of treatment dropout (e.g. loss of wages from missed work).

According to the results of a study in Mumbai, India, women who dropped out of treatment did so because of household responsibilities, and because they wished to keep their condition secret (Nair et al., 1997). Among the primary reasons given for dropping out of treatment in Vietnam, men listed a lack of understanding of the importance of sustained treatment and concern about the adverse economic impact of TB care and treatment on their household finances (Johansson et al., 1999). Perceived benefits were outweighed by the social and economic costs. Women cited concerns about interactions with health-care providers and social stigma as the main reasons for their default.

Not all factors that influence adherence to treatment exhibit such pronounced gender bias; some factors affect both men and women equally. Getahun and Aragaw (2001) identified clinical improvement as the most common reason for treatment discontinuation in their community-based study in Ethiopia, followed by the distance of the treatment facility. Here family and social supports were found to be a critical element in promoting treatment adherence.

Although concern about the economic impact of absence from work is a factor frequently emphasized for men, experience has shown that strategies to overcome this particular barrier may offer effective options for improving treatment adherence in both men and women. An example from South Africa has demonstrated businesses, as well as workers, can benefit from the provision of health-care services in the workplace. The company, Anglo Gold, estimated that

it was losing US\$ 410 per year per TB patient in lost shifts. By introducing a comprehensive TB control and prevention programme, it not only saved US\$ 105 per employee, but also reduced the occurrence of active TB among HIV-positive workers (WHO/ILO, 2003). In Bangladesh, Youngone Industries, the largest employer in the high-prevalence Chittagong Export Processing Zone, developed a comprehensive TB programme that eliminated the TB treatment default among its predominantly female workforce (WHO/ILO, 2003). This programme, which was developed as a component of a broader DOTS strategy in the national TB programme, protected employees by ensuring they could not be dismissed because of a diagnosis of TB, offered free treatment and provided a commitment that patients could return to work as soon as their sputum tested negative for TB. In addition to on-site laboratory facilities, the programme provided educational and counselling services that addressed a broad range of issues, from hygiene to stigma. Given that recent estimates put the cost of TB at around US\$ 12 billion annually in terms of lost labour productivity alone (WHO/ILO, 2003), the benefits of such policies are potentially very great indeed.

Box 5

Recommendations for research: treatment adherence

- Gender-specific impediments to treatment adherence, which appear to have a greater effect on men, require more in-depth study. Hypotheses based on known gender differences, such as the premise that enhanced social vulnerability and greater stigma affecting women may lead those who come for treatment to pursue it more diligently, should be tested.
- Given that patients in some settings avoid clinics for fear of disclosure of their condition, future research should investigate the impact on adherence of directly observed treatment performed outside clinic settings, using family members, private practitioners, midwives, cured patients or other community members. Setting-specific comparisons of clinic-based and community-based DOTS are also required.
- To respond to the problems for men of clinic attendance and treatment adherence, the value of TB diagnostic and treatment services in the workplace should be analysed in greater detail. There is a need to consider both case identification and treatment outcomes of patients with reference to added convenience and also employer responses in terms of the potential economic benefits of less absenteeism, greater productivity and reduced travel expenses.

7. Treatment outcome

As women are more likely than men to adhere to treatment, one would expect women to have more positive treatment outcomes. The gender-specific barrier hypothesis also suggests that women should outperform men in adherence and illness outcome. Research in both Africa and Asia confirms the anticipated links between adherence and outcome. For example, among study participants in three urban and rural districts of Tanzania (Hai, Morogoro and Kinondoni), 5% of women and 6% of men defaulted from treatment, and following treatment, 67% of women, compared with 63% of men, were free of TB ($P < 0.05$) (HealthScope Tanzania, 2003). In Thailand, multivariate analysis revealed that, for the same course of treatment, being male was a strong risk factor for unsuccessful treatment outcome, even after allowing for o t h e r

confounding variables (Pungrassami et al., 2002).

Adherence to treatment over the first three months has been shown to be an especially critical determinant of cure. The decision of patients to complete the full course of treatment involves an accommodation of personal perceptions of health status and risk, which are in turn influenced by cultural and personal meanings of sickness and cure. This accommodation is a kind of subjective cost-benefit analysis in which the personal, social and financial burdens are weighed against the expectations of a cure (Liefoghe et al., 1995). Identifying the critical determinants of analyses of this type for women and men will help to guide the development of more effective programmes for TB control.

Box 6

Recommendations for research: disease outcome

- More research is needed to unravel the mix of factors that interact to produce the more favourable treatment outcomes for women. Research of this nature needs to consider the determinants suggested by gender-specific motivations and the barrier hypothesis.
- Gender-specific determinants of poor treatment outcome need to be identified and their mode of action understood in order to develop appropriate policies to counter their effects.
- The study of gender effects should begin but not end with comparisons of men and women. They should explain gender differences by studying interactions that clarify gender-specific effects of explanatory variables on TB-related stigma, provider and patient delay, and treatment outcome.

8. A multi-country study of gender and TB

Recently completed field research in a four-country collaborative study of gender and TB, supported by the United Nations Development Programme/World Bank/WHO Special Programme for Research and Training in Tropical Diseases (TDR), has examined many of the questions posed by the gender-specific barrier framework that guides the present review. Participating research institutions include the Equi-TB Knowledge Programme in Lilongwe, Malawi; the Tuberculosis Research Centre in Chennai, India; BRAC (formerly the Bangladesh Rural Advancement Committee) based in Dakha, Bangladesh, and now active throughout the country; and Centro Internacional de Entrenamiento e Investigaciones Médicas (CIDEIM) in Cali, Colombia. The Bangladesh sites are exclusively rural, the Malawi sites both rural and urban, and the remaining sites exclusively urban.

As part of the TDR study, the TB-related experience, meaning, and behaviour and self-perceived stigma in men and women were compared. Locally appropriate variables for study were identified from experience at each of the sites. Indicators of stigma were analysed individually and collectively (i.e. as an index) in order to quantify the magnitude of stigma affecting patients and to identify its main determinants. The analysis of the individual features of stigma considered their frequency and the narra-

tive context that explained the nature of social concerns about TB. Specifying the prominence and distribution of variables facilitated gender study and comparisons within sites and across sites, and examination of the practical implications of sociocultural aspects of TB and the social responses to it. It also indicated how to identify sociocultural determinants of patient delay and provider delay.

Broadly speaking, the results obtained from these studies are consistent with features of the gender-specific profiles of TB reported in the literature reviewed above. Nevertheless, the study also revealed some interesting differences between the study locations. Blood in sputum was reported more frequently by men than women in India, and it was identified as the most troubling symptom by men, but not women, in both India (12.1%) and Bangladesh (9.6%). It was not, however, a distinctively male concern in either Malawi or Colombia. Concerns about the impact of TB on earnings and income were male issues in the two south Asian sites, and also in Malawi. One or more of a variety of vague, non-specific somatic symptoms predominated in women at all sites, including fever, chest pain, breathlessness, weakness and other physical symptoms.

Of the perceived causes of TB, abused substances – either smoking, alcohol or other drugs – dominated the

male responses at most sites. Bangladesh was a notable exception, where only 1 of 100 respondents identified alcohol as a cause of their TB. In Colombia, alcohol, drugs and smoking were all mentioned frequently by the vast majority of respondents, but only smoking was reported more frequently by men as a cause (men, 94.0%; women, 81.3%; $P < 0.01$). Only in Malawi, where TB is most closely linked with HIV/AIDS, did more women emphasize sexual contact as the cause of their TB than men (women, 28.0%; men, 4.0%; $P < 0.01$). Narrative accounts indicated the particular nature of women's concerns in settings where HIV/AIDS is rampant. "Maybe because my husband...he is a driver, maybe where he was going he was with other women." A vulnerability to the effects of their husbands' behaviour was a pervasive concern for many women in Malawi.

The men who identified sexual contact as the cause of their TB were not only fewer in number in Malawi, but their accounts were also qualitatively different, focussing on their active, rather than passive, role and power in the relationship. Men typically focussed on the TB itself, rather than on their vulnerability to the

effects of their spouse's behaviour. For example, a man who identified sexual contact as a perceived cause explained, "I suspect that my former girlfriend passed the disease to me. I wanted to marry that lady ... but I did not know that she had TB. When I knew she had TB, I changed my mind and decided not to marry her. A few months later, I began coughing."

The multi-country studies also sought to examine the effects of gender and other cultural epidemiological variables on stigma. Multivariate models were used to identify specific explanatory variables for each of the outcomes of interest at each site. The analysis also considered interactions between each of these variables and a variable for sex (specified as women with reference to men as baseline), to identify not only the overall effects of gender, but also gender-specific effects of each of these variables (see Box 7, page 30). This approach to the study of sociocultural determinants is also applicable to more specific analyses of patient delay and provider delay (see Box 8, page 32). Further details from the cross-site analysis of the WHO/TDR studies in four countries will be presented in a forthcoming TDR report.

Stigma

Illness-related stigma refers here to social disqualification from full social acceptance by virtue of the identification of a person with TB, ignoring other aspects of this person's identity that might otherwise motivate compassion and support. Such stigma may be socially enacted, self-perceived, or anticipated by people with a stigmatized condition. EMIC interviews, which are locally adapted instruments for cultural epidemiological study, inquired about respondents' TB-related experience and indicators of self-reported stigma. Examining these collectively as an index of stigma, the investigators assessed and compared the magnitude of stigma and analysed its determinants. Narrative accounts in response to questions over the course of these interviews, which were maintained as a component of the data set, indicate the nature of stigma as reported by the respondent, and clarify the role of disease-specific, gender-specific, and site-specific features and determinants.

Findings indicated common cross-site and distinctive site-specific features of stigma. Particular concern about loss of social status was related to the overall index of stigma in Bangladesh, India and Colombia. In India, however, a gender-specific effect of that variable suggested that this was less of an issue for women, compared with men. This suggests that the social exclusion arising from the disease was more likely to be a novel experience for men, as illustrated by men's narratives such as:

"I have been given a separate plate for my use and I am using a separate mat to sleep by my family. Really this hurts me a lot."

For some of these men, such a recalibration of social status reverses the hierarchies of power in the household:

"This illness has affected my relationships within the family. My sister and brother are very nasty to me. My sister refuses to share her mat with me. My brother gets irritated when I cough."

In addition to this social suffering, male responses also indicated two additional concerns about dependency and responsibility. Some worried that their own dependency needs within the household might not be fulfilled:

"If my wife and son know about my disease they may even feel ashamed to talk to me. I may be asked to get out of the home."

Others burdened by a sense of responsibility spoke of their concerns about repercussions of the social response to their condition for the rest of the family.

9. Gender in health policy for TB control

A range of TB policy documents are briefly examined below in order to gain some indication of the extent to which public health programmes currently acknowledge gender-based issues and concerns. Particular attention has been paid to policies for the control of TB in the low- and middle-income countries.

Gender sensitivity is notably lacking in some of the most influential documents of globally active NGOs, which one might expect to be more attentive to social and cultural concerns. The International Union against Tuberculosis and Lung Disease, for example, has published an important and useful document, *Management of tuberculosis: a guide for low-income countries* (IUTLD, 2000), which is inattentive to gender. The WHO/ILO *Guidelines for workplace TB control activities* (2003) refers to women and TB in the workplace with only cursory consideration of gender. They do acknowledge, however, the importance of extending TB services to entire families and the importance of equal access to treatment for men and women. The *Amsterdam Declaration on Tuberculosis* makes no specific mention of gender (2000).

WHO's guidelines for national tuberculosis programmes (NTPs) make a number of recommendations and include operational strategies that acknowledge the importance of the social context of TB. Recommendations for national TB pol-

icy, however, have thus far been more concerned with the technical aspects of TB control and less so on the more sociocultural aspects. The guidelines emphasize the importance of each NTP developing a strong central unit, creating a programme manual, implementing a case reporting and recording system, initiating training programmes, developing networks of decentralized microscopy services, incorporating DOTS treatment services within the existing primary health care (PHC) system, assuring reliable drug and equipment supply systems, and drafting a plan for supervision (WHO, 2003c). They also recommend the development of IEC and social mobilization campaigns, the involvement of private and voluntary health-care providers, economic analysis and financial planning, and ongoing operational research (WHO, 2003c). Many, if not all, of these technically- and socially-oriented priorities for policy will benefit from the inclusion of a gender perspective.

With its focus on social and human rights issues at the global level, another WHO document, *Guidelines for social mobilization: a human rights approach to tuberculosis* (Hannum & Larson, 2001), examines the impact of TB on various vulnerable groups, including women, children, the poor, migrants, refugees and prisoners. This policy document elaborates key aspects of gender and relevant aspects of the sociocultural contexts of women's health, including stigma,

Box 8

Timely help seeking

Multivariate analyses of sociodemographic and sociocultural determinants of delay from first awareness of symptoms to diagnosis of TB were completed at three sites. In Bangladesh, cough and increasing age were associated with a longer delay, and social problems collectively were associated with a shorter delay. In India, female sex, a higher level of education, sexual contact as a perceived cause of TB, and prior help seeking in a healing temple were associated with a longer delay; cough, blood in sputum and concern about the course of illness were associated with a shorter delay. In Malawi, loss of job and wages, drug abuse as a perceived cause, and prior help seeking at an NGO clinic were associated with a longer delay.

The multivariate analysis also considered interactions between explanatory variables and sex (female compared with male). Findings in Bangladesh showed that women who had never been married, married women with marital problems, women reporting humoral perceived causes (heat-cold imbalance), and women giving prominence to social problems had longer diagnostic delays. In India, women who previously sought help from private doctors had longer delays; women with more prominent physical symptoms and prior help from traditional or magico-religious healers had a shorter delay. In Malawi, women with more prominent concerns about the course of illness and with prominent emotional symptoms had a longer delay; those with more prominent physical symptoms had a shorter delay.

These findings suggest that in Bangladesh marginalized social status and the prominence of traditional concepts to explain TB had a gender-specific effect in prolonging time to diagnosis for women. In India, prior help seeking from traditional healers and temples was associated with increased delay for the overall sample, but this was significantly less of a factor for women, possibly because traditional practices among women are more normative than for men. In Malawi, more prominent physical symptoms reduced delay and prominent emotional symptoms increased delay for women; these findings suggest greater sensitivity among providers to physical symptoms of TB, and they indicate a need to examine the role of the psychosocial impact of TB on both patient and provider delay.

discrimination, access to health services and issues of abandonment.

National programmes are encouraged to focus on practical indicators of programme success, including for example, high case detection rates, high cure rates and low levels of drug resistance; less attention tends to be given to questions about how gender and other social contexts might relate to such goals (WHO, 2003c). Some authors have suggested that insofar as vertical programmes may discourage intersectoral collaboration, it is difficult to motivate attention to gender-related issues or to implement gender-sensitive policy within them (Ogden et al., 1999). The Revised National Tuberculosis Control Programme in India, however, illustrates how vertical programmes in high-burden countries aim to move towards a more decentralized model and to make themselves more responsive to social and cultural contexts (Ministry of Health and Family Welfare, Government of India, 2002).

India's National Health Policy 2002 focuses throughout on the health of the poor, and dedicates a section to the health of women and related socioeconomic and cultural issues (Ministry of Health and Family Welfare, Government of India, 2002). The document acknowledges the importance of women's health as a major determinant of the health of entire communities. The policy endorses the need to expand the primary health care infrastructure to increase women's access to care. The policy also recognizes a need to review staffing in the public health service, so that it may become more responsive to specific needs of women. The priority of high-burden

diseases explicitly refers to TB, and the document acknowledges the need for "separate schemes, tailor-made to the health needs of women, children, geriatrics, tribals, and other socioeconomically under-served sections".

Such attention to society, culture and gender is, however, exceptional. Most national and international TB policy documents give these topics rather more perfunctory consideration. This largely reflects inattention to such questions in prior research, and consequently, a lack of understanding about how to achieve a gender-sensitive health policy. The Manual of the National Tuberculosis and Leprosy Programme in Tanzania (2003) provides a good illustrative example of the prevailing status of gender in NTPs (Ministry of Health, United Republic of Tanzania, 2003). Sections for which consideration of gender issues would be highly relevant, such as patient education, makes no reference to the specific vulnerabilities, problems, needs or strengths of either men or women. The manual does acknowledge the special needs of women with reference to biological sex differences, identified as "treatment in special cases", considering guidelines to therapy for pregnant or breastfeeding women, and for women who take oral contraceptives. The Manual of procedures which is intended to serve as a guide for the national TB programme in the Philippines makes no mention of gender or other issues specific to women (Department of Health, 2001). The South African Tuberculosis Control Programme practical guidelines (South African Department of Health, 2000) also neglects questions of both gender and the particular needs of women.

Nor is the lack of attention to gender issues a matter for the low- and middle-income countries alone. In the United States of America, the New York City Bureau of Tuberculosis Control similarly refers extensively to TB in pregnant women, HIV-positive women and breastfeeding women in their clinical policies and protocols (New York City Department of Health, 1999). A recommendation for counselling services for such women, however, would clearly benefit from more explicit consideration of gender issues.

It is difficult to comment on the diverse approaches to gender issues in local TB policies that exist internationally. One can no doubt find extreme examples of both insensitivi-

ty and sensitivity to gender. One innovative approach has been adopted by the Tuberculosis Research Centre in Chennai, India, which has been working with local filmmakers to produce dramas and documentaries that highlight the various options for clinic and community-based TB treatment. These depict in a poignant and socially-acceptable way the key gender-related problems and solutions. The films are used to stimulate discussion, promote awareness and indicate how families and communities may respond to TB. They show the ways in which the disease can affect women and men, the problems it imposes on families, and examples of how families and communities have responded.

10. Conclusion

The epidemiology and course of tuberculosis differs for men and women. Women progress from infection to active TB faster than men do, but the reported incidence of pulmonary TB among women is nearly always lower than for men. It remains unclear whether and to what extent these differences are a true reflection of disease incidence, as recent research from India suggests, or an indication of health system failures to detect and report female cases, as gender-based barrier models of limited access to health care and diagnosis suggest. TB case identification in DOTS programmes typically relies on passive case finding, based on symptomatic patients presenting to health centres for diagnosis by sputum smear and treatment. Clinical presentations of TB affecting men and women also differ.

TB gender research is concerned not only with clarifying differences between men and women in the biological vulnerability and pathophysiology of pulmonary TB; it also aims to elucidate the particular problems and significant sociocultural and socioeconomic barriers men and women face when seeking TB care and treatment. Although research has begun to clarify the point, we do not yet fully understand the gender-specific symptomatology of TB, which must take into account variation across cultures. If unrecognized in the routine course of clinical assessment, sex-specific clinical presentations of TB may interfere with diagnosis and timely treatment of women. In addition, further

research is required to better understand men's underutilization and timely access of health services for diagnosis and treatment, and their problems with adherence.

Many of the studies considered in this review have begun to address these questions, and more with a practical focus on programme-specific operations are needed. We know that for unexplained reasons, women are more likely than men to adhere to treatment and to complete a full course. Consequently, women who reach treatment are also more likely than men to be treated successfully. Research on gender and TB now needs to focus on ways of enhancing the effectiveness of case finding for women, preventing treatment default, and identifying operationally precise reasons for default among men and women. The stepwise gender-specific barrier framework guiding this review helps to ensure a practical focus for such research. We have also indicated how basic epidemiology, health social sciences and cultural epidemiology have addressed these aims in a four-country collaborative study supported by TDR.

Because most people with TB can be successfully treated and cured, the challenge for health policy-makers and health systems is especially poignant. Successful control of TB relies on competent services and the availability of effective medicines, which are accessible and attractive to people who need them, and that clinical services are well managed and

able to fulfil their obligations. Attention to issues of gender is vital to achieve such goals generally, but especially for TB because questions of gender norms and inequality are central to the experience, meaning and behaviour of people with this disease in the low- and middle-income coun-

tries where this disease takes the greatest toll. A commitment to the gender-sensitivity of interventions, guided both by needed research and by applying in DOTS programmes what we already know, will help to ensure that TB control is as effective as it can be for everyone.

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