Social and cultural dimensions of gender and tuberculosis

TUBERCULOSIS affects millions of people worldwide, mostly the poor and impoverished, women and men alike. Notwithstanding the urgent need for additional tools—including new drugs, diagnostics and vaccines—unmet social challenges remain high priorities for effective TB control. Scientific research supporting efforts to meet programme goals requires consideration of the biology of infection, health system performance and the social and cultural contexts that affect the illness and treatment behaviour of people with TB. Gender has become an increasingly important aspect of socio-cultural studies of the disease burden and control in low- and middle-income countries, and it is an especially important consideration for TB.

Although tuberculosis is a leading cause of mortality among women, higher rates and worse outcomes are typically reported for men in much of the world. Gender influences the clinical presentation and illness-related experience, meaning, behaviour and treatment outcomes. Both women and men face gender-specific barriers to TB diagnosis and care. The pandemic of HIV and AIDS is increasing the incidence of TB, and the biosocial links between TB and HIV in low-income settings of disease-endemic countries further enhance stigma, lending it more power and new meaning that require attention. The nature of its impact varies in different settings, and socio-cultural features of gender require a thorough scientific analysis for locally effective programmes.

Historically, gender has not received adequate attention in social studies of TB. Although all reporting countries have maintained sex-disaggregated data since 1997, many do not use it enough for research or action on the ground. Over the past decade, however, recognition of that point has motivated some researchers to argue for attention to the priority of gender for TB control.1,2 Uplekar and colleagues developed a stepwise barrier framework that suggests ways of considering gender differentials from occurrence to help seeking, diagnosis, treatment and outcome.3 The TDR-funded multi-country study of gender and tuberculosis presented in this special section of the Journal is an example of a long-term commitment to gendered social science research by the UNICEF/UNDP/World Bank/WHO Special Programme on Research and Training in Tropical Diseases (TDR).4

Although such commitments are establishing the priority of gender on the agenda of health social science research, questions about how to assess its practical impact on essential features of disease control have been a challenge from the outset, especially for multi-country studies in diverse cultural settings. Comparison of the basic epidemiology for men and women and evaluation of programme data are typically first steps, but documenting does not necessarily explain the relevance of social and cultural dimensions of gender for TB control. The nature of social exclusion, the emotional impact and historically rooted cultural meaning of the disease, the importance of distinctive clinical presentations of men and women and the influence of gender roles on access to household resources and outside health care are all relevant but difficult to discern satisfactorily solely by standard quantitative methods.

While consideration of sex differences based on the classical epidemiology and monitoring of health system performance is essential, such approaches should be complemented by efforts to explain the nature of differences and test relevant hypotheses that are capable of contributing to the practical impact of programme action that takes gender differences into account to improve outcomes of programmatic concern. Development of some means of quantifying various social and cultural dimensions of TB-related experience, meaning and behaviour facilitates comparison between men and women in different regions. The need for a qualitative account of relevant contexts and analysis of socio-cultural factors that influence relevant illness behaviour—considering the role of gender directly and as an effect modifier interacting with features of illness explanatory models—further recommends a cultural epidemiology employing a mixed methods approach.

Drawing on experience from other areas of health social science research, particularly in mental health,5 such a framework was used to investigate several aspects of gender and tuberculosis that are reported here. Cultural epidemiology studies the distribution and prominence of categories of illness experience, meaning and behaviour with reference to the prominence of locally valid categories and illness narratives. The distribution of these variables and narratives describes their social and cultural context, and it explains the influence of social and cultural features of illness on programme effectiveness. Integration of qualitative and quantitative research methods provides a descriptive account, facilitates comparisons and clarifies the cultural basis of risk, course and outcomes of practical significance. For the study of TB, the approach has focused on gender differences and their impact with reference to patterns of distress (i.e., patient-prioritised symptoms and the social and emotional impact of illness), patient-perceived causes that indicate the meaning of TB, social stigma and help
seeking before coming for treatment in a clinic of a working TB control programme.

Cross-site analysis highlights the importance of social and cultural dimensions locally, highlighting distinctive features and both common and local manifestations of cross-cutting themes. Four groups of investigators participated from the outset in the multi-country studies supported by TDR. They represented regional interests in rural and urban South Asia (Bangladesh and India, respectively), HIV-endemic Southern Africa (Malawi) and South America (Colombia). Each of these studies was concerned with implications of gender for functioning programmes, and the reports in this special section of the Journal present findings from comparative analysis of their findings. Although these clinical studies cannot represent countries as diverse as those in which these programmes operate, they do indicate an approach for taking socio-cultural features of TB and gender into account to enhance the capacity and performance of programmes locally.

After a review of research in the field of gender and tuberculosis, six papers present findings based on the cross-site analysis of the cultural epidemiology of gender differences in the illness experience, perceived causes and prior help-seeking experience. Two papers present findings from studies in Bangladesh, India and Malawi that provide a descriptive account of the cultural epidemiology and analysis of determinants of delay from first awareness of symptoms to diagnosis. A third report also considers the fourth study in Colombia and focuses on patients’ self-perceived stigma. It identifies features of illness explanatory models that contribute to stigma and considers their qualitative effects.

Findings show that TB control must be attentive to the diversity of local gender-specific clinical presentations and the impact of depressive features of the social and emotional burden of TB. Combined effects of setting and gender contributed to the isolation of women in Bangladesh from concern about the risk of spread regardless of treatment. Delayed diagnosis and start of treatment were associated with status of being a housewife, a married woman or merely being a woman, respectively in Malawi, India and Bangladesh. Gender-based stigma differentials also differed by site qualitatively, reflecting urban (India) and rural (Bangladesh) differences in South Asian sites, and the impact of HIV/AIDS co-morbidity on the gendered meanings of TB-related stigma in Malawi. Collectively, these studies show how public health research may integrate interdisciplinary priorities and methods. Effective TB control and the broader interests of gender and health demand nothing less.

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