Gender and Tuberculosis Control: Towards a Strategy for Research and Action

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Executive Summary

The magnitude of the global tuberculosis (TB) epidemic is enormous. About a third of the world’s population is infected with *Mycobacterium tuberculosis* and an estimated 8 million new cases and 2 million deaths occur yearly due to the disease. In most of the world, more men than women are diagnosed with TB and die from it. TB is nevertheless a leading infectious cause of death among women. In 1998, about three-quarters of a million women died of TB, and over three million contracted the disease, accounting for about 17 million disability adjusted life years (DALY). As tuberculosis affects women mainly in their economically and reproductively active years, the impact of the disease is also strongly felt by their children and families. The mortality, incidence, and DALY indicators do not reflect this hidden burden of social impact. In view of the substantial burden and women’s particular health service needs, a strategy is needed to study and consider the impact of gender on operational aspects of tuberculosis control.

The term gender encompasses features of males and females that are socially constructed, distinct from those features that are biologically determined (sex-linked). Higher tuberculosis notification rates in men may partly reflect epidemiological differences — differences in exposure, risk of infection, and progression from infection to disease. Some studies indicate that women may have higher rates of progression from infection to disease and a higher case fatality in their early reproductive ages.

Higher rates reported for TB in young and early middle-aged women in industrialised settings earlier in the century raise a question whether under-detection of women TB patients in poor countries may be due to various problems of access to care. If gender inequalities in TB are due to problems of access and underutilisation of available services, these problems should be clarified and remedied by TB programmes. To do so, it is essential to determine the extent to which the observed sex differences in tuberculosis notification rates in low income countries arise from distinctive obstacles faced by men and women.

Health seeking and treatment behaviour of men and women suffering from TB is largely determined by how he or she and those around perceive the symptoms, regard the diagnosis, accept the treatment, and stay with it. Gender may influence each of these and affect detection of the disease and its outcome. A framework was developed taking into
account the various steps and barriers encountered from onset of symptoms through diagnosis and treatment to cure from the disease. Its application to data available from routine records at seven different TB projects in diverse Asian settings provided useful information. Several factors have clearly different effects on the care seeking and treatment behaviour for TB among men and women. These include self-image, status in family and society, access to resources, manifestation and expression of symptoms, and stigma associated with TB. With respect to treatment in the health system, gender differences are also notable for choice of provider, provider bias, sputum examination, non-acceptance of diagnosis of TB. While women may have to negotiate more barriers is seeking treatment for TB, they tend to be more compliant than men in taking it.

Gender-related barriers to TB care may vary greatly in diverse settings. Understanding the variety and details of these barriers requires a multi-site investigation employing a generic protocol adaptable for local use. Such a protocol, incorporating quantitative and qualitative research methods, will help local TB programmes to identify gender-related barriers to access. Research comparing multiple sites will identify common and distinctive barriers to effective care and ways to surmount them. Interventions in programme operations would then be tested and implemented. If they work, guidelines following from this experience should be made available to assist TB programmes to minimise gender disparities in access to care and case management. The steps for such a research strategy may be summarised as follows:

1. Re-examine age and sex-disaggregated data from past surveys and data maintained by TB programmes to clarify the magnitude and nature of gender disparities. Undertake new epidemiological surveys to establish a "gold standard" of sex-ratios.

2. Develop a generic protocol incorporating appropriate epidemiological and social science methods to identify barriers and to confront gender-related problems of access to and care within TB programmes.

3. Adapt the protocol for comparative study in multiple and diverse settings with a functioning TB programme, willing programme staff, and local research capacity. Opportunities for comparison in diverse social and cultural settings will clarify the context and variability of gender-related barriers, and indicate practical solutions.

4. Pilot proposed interventions for gender-sensitive TB control, and compare experiences in different settings.
5. Develop guidelines and tools for TB programmes to minimise gender disparities.

Such a strategy follows from recent attention and recognition of the broader impact of gender on health and development. It is needed to clarify the impact and nature of gender differences and to improve the effectiveness of TB control programmes.
1. Introduction

Broadly, gender is "what it means to be male or female, and how that defines a person's opportunities, roles, responsibilities and relationships" [1]. Since the concept of gender, distinct from sex, was developed during 1970s, extensive literature has accumulated on gender in health and development [2,3]. Traditionally, women have had to face much greater health risks; confront many more constraints and make do with much fewer opportunities in trying to resolve their health needs than men [4]. Gender also plays a role however in men's health problems – their proneness to accidents, addiction, and violence for instance. As they affect women, gender relations reflect power relations: within each category 'woman' and 'man' is a hierarchical ordering of status that leads to inequity in the health and well being of women in relation to men.

1.1 Gender, Poverty and Health

Worldwide, over a billion people live in absolute poverty [5], seventy per cent of these are women [6] and three quarters of the burden of ill-health among them is attributable to diseases of poverty, of which infectious diseases are a major part [7]. Health risks of poverty are far greater for females than for males. Everywhere, women control fewer productive assets, work longer hours, earn less income than men and face unique reproductive health threats. And yet it is they who meet 40 to 100 per cent of a family's basic needs [8]. Poverty among females is more intractable, and their health more vulnerable to adverse social and environmental conditions [9]. Aggregate global statistics often mask important gender disparities and geographical differences. Mortality rates for young girls are markedly higher than for boys in poor countries [10]. In India, for instance, every sixth infant death is attributable to gender bias; deaths of girls under age 5 exceed those of boys by nearly 300,000 annually; and women aged 15 and older die from communicable diseases at higher rates than men in the same age groups [11].

1.2 Women and Communicable Diseases

Attention to women's health in poor countries has been motivated largely by concerns for reproduction. Broadening the concept of women-focused "family planning" to a more comprehensive "reproductive health" required decades to deliver. The Special Programme for Research and Training in Tropical Diseases (TDR) of WHO has contributed much to identifying and understanding gender issues in tropical diseases; recognising that although
both males and females in poor countries suffer from poverty, deprivation and class inequality, women are at a far greater disadvantage than men due to social and structural factors [12,13,14]. A report on female morbidity and mortality in sub-Saharan Africa concluded that tropical infectious diseases generate a greater burden for females than for males, and that although they are often viewed as episodic, tropical infections produce large burdens of disability. The burden of STDs, including HIV infection, is definitely greater for females than for males and the disparity is growing [15].

1.3 Gender and TB

The magnitude of the global tuberculosis epidemic is enormous. About a third of the world’s population is infected with *Mycobacterium tuberculosis*. In 1998, about three-quarters of a million women died of TB, and over three million contracted the disease, accounting for about 17 million disability adjusted life years (DALY). It is the greatest single infectious cause of death in women worldwide [16]. Literature on gender and TB is scanty: only a few succinct reviews on epidemiological and socio-cultural gender differentials and a report of a recent international workshop on the subject [17,18,19]. Worldwide, more men than women are diagnosed with TB. It is not clear to what extent these differences result from biological factors, socio-cultural contexts, and from under-recognition of TB among women due to poor access to care.

2. Aims and methods

This paper examines the impact of gender on the epidemiology of TB and access of men and women to health and TB care. It is based on a review of available literature and discussions with a group of experts. To get a feel of ground realities, the authors visited four tuberculosis programmes in South Asia, the region which contributes most to the world’s burden of tuberculosis. The sites visited included a National Tuberculosis Programme (Nepal), a successful DOTS programme implemented by a large NGO that is concerned about and responsive to gender issues (BRAC, Bangladesh), a TB project run by a voluntary organisation in rural areas of Western India (Gujarat) and a public-private mix (PPM) project based in a city private hospital (Hyderabad, India). The visits indicated how the issue of gender and tuberculosis is perceived by health workers at various levels. At each site discussions were held with with programme managers, health workers, and also a few men
and women patients. Data available to fit into a conceptual framework that evolved (figure 1) in the process of our literature search and discussions was collected (Table 2-4).

This paper first summarises what is documented on gender and TB. A framework to guide study of gender differentials in tuberculosis is then presented. An attempt is made to fit some facts and figures within the framework, based on information available in the literature and that obtained from the field sites. It indicates a strategy for further study of relationship between gender and TB and a framework to guide intervention and programmes. The key consideration in outlining the strategy has been to focus on what is possible and feasible within TB control efforts before addressing problems related more to general health services, health systems, and beyond.

3. Background

The impact of gender on health has been largely ignored and in TB research and control efforts, gender was not just missing, it was also considered unnecessary. In the last few years, however, as TB re-emerged onto the international and national public health agendas, inter-disciplinary studies and control efforts have begun to focus on the role of gender for this disease.

In May 1998, an international research workshop on Gender and TB, convened by the Nordic School of Public Health brought together scholars, practitioners and policy makers concerned with tuberculosis. Key issues from were presented from various perspectives and discussed. The book produced from the workshop, represents a resource for setting the agenda for future research on the subject [19].

Epidemiological surveys have shown the prevalence rates as well as tuberculin positivity among women to be consistently lower after the age of 15. Some of this difference is attenuated because women of reproductive age are at greater risk of progressing from infection to disease than are men of the same age [21]. Failure to consider the role of gender in TB perhaps followed from interpretation of available evidence suggesting that women are simply less likely to develop TB than men.
3.1 Current concerns

Although the epidemiological findings stand, questions about their implications require consideration and research. For example, female mortality due to TB is more than that for all causes of maternal mortality combined [17,18]. Also, although the overall prevalence of pulmonary TB is lower in women, progression from infection to disease is as much as 130% higher in women between the ages of 10 and 44 years, and case fatality rates are 27 - 41% higher in women and girls between 5 and 24 years of age [18]. These numbers indicate that, while women may enjoy some kind of protection against TB, this protection may be offset by biological and sociological vulnerabilities at certain life-stages. This may lead to accelerated morbidity and mortality, as well as delays in treatment-seeking and/or differential treatment once they seek help from the health care system. Smithsummarises the situation: gender of itself is not the cause of morbidity and mortality in TB, but is a powerful indicator of disadvantage, a marker of the many factors that influence health and the utilisation of health services [22].

Other data that have recently sounded alarm bells highlight TB notification rates in low-income countries. In retrospect we can see that, in Europe and America in the middle of the twentieth century when overall Annual Risk of Infection (ARI) was high, women between 15 and 35 years of age had higher TB notification rates than men of the same age group. In contrast, in many low-income countries today, prevalence in men exceeds that in women after age of 15 years, although overall notification rates for both sexes combined are similar to those in Euro-America in the mid-1900s. These findings suggest the possibility that cases of tuberculosis among women are being under-reported in developing regions [18]. The likelihood of under-reporting among women in low-income countries was further highlighted by a study comparing active and passive case-finding in which women with tuberculosis were under-notified to public health authorities when relying on passive case finding [23].

Thus a number of scientific, social and cultural changes in the public health landscape have combined to create a new environment of increased willingness to question the assumptions about gender and TB. The increased international attention to TB coincided with an increased interest in inter-disciplinary working in infectious diseases, which itself led to the creation of various models for a “gender analysis in health” [12]. Some of these models relate to the study and control of specific infectious diseases such as leprosy, malaria, leishmaniasis and STD/HIV, and others attempt to provide more generalised models
[3,24,25]. It is useful to highlight the key dimensions of common ground as a broad framework, with which to think about the findings presented below, as well as the relevance of the project overall.

3.2 What is Gender Analysis?

At root, a gender analysis in health is concerned with asking how and why inequity occurs in health; in other words, a gendered analysis in health takes the emphasis away from questions of organic/biological causality and concentrates on explaining the differential constraints experienced by women and men in access to health and health care. The gender perspective facilitates a more contextualised understanding of differences between women and men in relation to:

- rates of and vulnerability to infection;
- differences in access to and use of available health care resources;
- differences in the effect of the social meanings, especially stigmatisation, of infectious diseases;
- the effects of disease on women as primary health care providers in their homes; and
- key dimensions of structural difference based on factors such as age and social status (including but not limited to economic status/class).

4. A Conceptual Framework

Illness typically proceeds along a course from experiencing symptoms to seeking help and taking treatment either for relief or cure. In acute illnesses, like Flu, the time course is short: a person having bodyache and fever may very soon take a handy pain killer and rest awaiting relief and cure. In a chronic illness like tuberculosis however, the sequence of events is more variable and dependent on various inter-related factors. This course of events may be captured through a patient-centric approach in what may be called a "health beliefs model". Health seeking and treatment behaviour of a patient is largely determined by how he or she and those around perceive the symptoms, receive the diagnosis, accept the treatment and abide by it. And gender could greatly influence each of these and become an important determinant of the outcome. Another approach may be biomedical through an "infection-disease model" wherein gender could be a significant factor in determining vulnerability to infection and development and progression of disease. There can be a third "health services
model" which combines the essence of both approaches mentioned above. Moreover, it may help a health provider to understand service-related gender differences and ask questions in order to attempt to address such difference. This is illustrated in Fig. 1, which attempts to provide a conceptual framework to study gender differentials in TB care. It illustrates the process of attrition that occurs as people move through the various steps of TB disease and treatment, accounting for sex differences at each stage. The space between successive columns (A to G) represents determinants of patient’s progress from a previous step to the next. The vertical dashed lines (0 to 6) represent barriers to progress and may be said to be responsible for the “depletion” along the course of the disease.

To illustrate, column C represents TB suspects referred to a TB service. These will be men and women suspects; a question arises about the sex-ratio among TB suspects presenting to a TB service. It is partly determined by the sex-ratio among symptomatics presenting to a general health service (column B), which in turn depends on the sex-ratio among chest symptomatics prevalent in a community (column A), and partly by differential barriers men and women face in presenting to a health service (barrier 1), and in getting referred to a TB service as suspects (barrier 2). Like wise, the sex-ratio among those diagnosed as TB (column D) will reflect and depend on sex-ratio among TB suspects (column C) and partly for reasons hidden in barrier 3; for instance, women may be embarrassed to provide sputum, or providers may send more men than women for sputum examination. The columns A to G thus represent mainly clinical, statistical and epidemiological questions while the dashed lines broadly indicate nodes for social science enquiry. The horizontal arrows indicate the process of movement which begins even before symptoms are expressed and presented and continues often beyond the disease outcome, as a result of persistent morbidity and stigma.

4.1 Applying the framework

Unfortunately, many of the data required to model tuberculosis according to this framework were not available at the sites we visited. The data that were available, though incomplete, provide a useful account of the situation nevertheless. Some of the relevant research questions that arise are presented in Table 1.
Figure 1 - Gender Differentials in TB: A Conceptual Framework

Columns = Sex Differences; Vertical Lines = Gender Related Barriers
<table>
<thead>
<tr>
<th>TB control Issue</th>
<th>Are there gender differences regarding (and if so, what are risk factors/reasons)</th>
<th>Research methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case finding</td>
<td>Help seeking for chest symptoms; delay? Proportion of persons with chest symptoms having tuberculosis? Patterns of referral for appropriate treatment?</td>
<td>Community study of untreated people with chest symptoms Clinic study of patients with tuberculosis and other respiratory diseases regarding help seeking and diagnostic delay</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Proportion of patients with chest symptoms receiving sputum examination? Proportion of the above giving sputum for examination Diagnosis with positive sputum smear? Other diagnosis?</td>
<td>Survey of outpatients Clinic record reviews Review of laboratory registers</td>
</tr>
<tr>
<td>Provider treatment practice</td>
<td>Initiation of appropriate treatment? Accessibility of appropriate drugs? Affordability of drugs? Style of treatment (e.g. Directly observed)?</td>
<td>Observation of clinic practice Clinic cohort studies</td>
</tr>
<tr>
<td>Patient treatment behaviour</td>
<td>Acceptance of diagnosis? Willingness to initiate treatment (initial default)? Adherence to treatment?</td>
<td>Clinical record reviews Case studies Community follow-up of former patients</td>
</tr>
<tr>
<td>Outcome</td>
<td>Various outcomes: cure, failure, dropout, death?</td>
<td></td>
</tr>
</tbody>
</table>
4.2 Reporting ill health
(Barrier 0 and Column A)

Among affluent societies, in general, women have higher levels of almost all indices of morbidity and utilisation of health services [26]. Routine morbidity data are unavailable in poor country settings; large surveys generally show similar or more reported morbidity and better utilization of health services among men as compared to women [27,28,29]. Smaller studies with more in-depth enquiry succeed in eliciting higher morbidity among women probably accounting for confounders like smoking, occupational exposure, indoor air pollution and so on. [30,31]. The lower reporting of general morbidity by women, is also considered to be due to the “culture of silence” -- a tendency to bear pain and suffering silently, constraints of communication, “internalisation” of low morbidity states, and a perception that what cannot be redressed need not be reported [30,31,32,33,34]. More important for TB control is respiratory morbidity. Here too, large surveys show that more men than women suffer from respiratory symptoms [28,35]. Smaller studies, however, have been able to show more substantial rates of respiratory morbidity among women [31]. One such study shows higher respiratory morbidity among rural women compared to rural men with respiratory morbidity, increasing with age among men but reaching a peak at mid and late forties among women [36].

4.3 Accessing health care
(Barrier 1 and Column B)

Gender differentials in the experience and expression of illnesses may play a role in accessing care. In poor countries women report sick less often than men do, and have more barriers to cross before accessing general health care services, whether public or private. In urban and rural areas alike, women’s preference for private practitioners including paramedics and traditional healers has been demonstrated in several studies in South Asia [28,29,31,37,38]. A striking finding is the greater use of the private sector and avoidance of public health services by women in the 15-24 age group. Proximity, convenient timings, cordiality and confidentiality attract women to private sources of care while emphasis on family planning seems to alienate them from government clinics [30,39,40]. Several other factors like long waiting times, poor quality of care, inadequate staff, lack of female providers and unfriendly attitude of health functionaries have all been reported as limiting access to public health facilities, especially for women [41]. With no recourse to public services and no resources for the private services, it is the poor and poor women, in particular, who have to suffer the most. The village-based female health workers of BRAC perceived that it is
women who are weak, it is they who fall sick more often and yet it is they who delay coming to health services, or do not come at all.

A sociological study undertaken in India in the sixties found that women having radiological shadows of TB did not report chest symptoms to the same extent as men [42]. In another survey, half the respondents who reported illnesses had not sought any therapy [35]. Women may be even less likely to seek treatment for cough, a symptom commonly reported but less often acted upon [43]. The problems of access may be compounded for older age groups due to restricted mobility [44].

At the sites visited, there was no disparity in the attendance of men and women at general health facilities. In three out of five of these places, women slightly outnumbered men [Table 2]. Where data disaggregated by age were available, the ratio of women to men exceeded one among the middle age groups, was almost one among children but was much less than one among people in their twenties as well as those above 65. The corresponding ratios among patients with chest symptoms attending clinics were similar.

### 4.4 Accessing TB care
(BARRIER 2 AND COLUMN C)

Sex ratios and age structure among chest symptomatics presenting to TB services not a part of routine reporting in several programmes, can provide very useful information that will indicate the extent of “filtration” that takes place in the process of patients being directed from general health services to TB diagnosis and treatment clinics. Both patients and providers may be responsible for delays in getting into TB care.

A study from Nepal showed that active case finding for tuberculosis brought more women and older people under care who would have been missed by passive detection approach [23]. Another study showed that more women with chest symptoms attended mobile sputum microscopy camps than conventional health centres and clinics [45].

Interestingly however, the clientele of the PPM project in Hyderabad, India presented a different age-sex structure. As mentioned above, this is the only private health facility, which is operating a public-private mix for TB care. The patients attending the clinic are referred by
male and female private medical practitioners practising in the vicinity. In contrast to public health services, younger women of 15-24 were seen to be in higher proportions here [Table 3]. While the overall M:F ratio was 1:0.8, the sex ratio among patients referred by private practitioners was 1:1 and that among patients referred by female private practitioners was 1:2. It appears that women with symptoms suggestive of TB and young women in particular, opted to seek help of a neighbourhood private practitioner, preferably a female one.

When patients who report with chest symptoms to any health provider are referred to a TB care facility for investigations and treatment, they may not always follow the referral advice [46]. The reasons for this could be many: apprehensions about the disease and its lengthy and expensive treatment, lack of resources, stigma, non-acceptance of the probable diagnosis and shopping for an “acceptable” or “better” diagnosis, problems of access and support [41,47].

On the provider-side, it is known that a good proportion of symptomatics reporting are never advised to have sputum examination at all [48,49]. Whether this might include more women needs investigation. Women may perceive or report their symptoms differently from men, and this may mean providers fail to suspect the disease in them. A common reason given by the programme managers at the BRAC to explain why they had fewer women TB patients was the very high level of suspicion of TB which existed because of BRAC’s education and information programme in communities where the impact of stigma on women was worse. This was why, they felt, when women developed chest symptoms, they did not seek help for it since they were worried about being labeled as TB patients.

4.5 TB diagnosis
(Barrier 3 and Column D)

The gender disparity in simply advising a sputum examination to all those having symptoms suggestive of tuberculosis was startling in the NGO project in Gujarat. Two out of every 3 men presenting to the clinic with chest symptoms were given a sputum examination but only 1 of every 3 women was advised similarly [Table 2]. This information surprised the programme managers who had never looked at the figures disaggregated by sex since the possibility of a disparity had never occurred to them.
### Table 2: M:F Ratios from Sites Visited

<table>
<thead>
<tr>
<th>Site</th>
<th>General outpatients (1)</th>
<th>Outpatients with resp. symptoms (2)</th>
<th>Patients undergoing sputum exam (3)</th>
<th>Patients testing sputum positive (4)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>F</td>
<td>M:F a</td>
<td>M</td>
</tr>
<tr>
<td>Govt. hospital, Nepal</td>
<td>8923</td>
<td>9083</td>
<td>1:1</td>
<td>22</td>
</tr>
<tr>
<td></td>
<td>(2.5)</td>
<td>(1.9)</td>
<td>(1:0.8)</td>
<td>(7.1)</td>
</tr>
<tr>
<td>NGO clinic, Nepal</td>
<td>7310</td>
<td>6228</td>
<td>1:0.8</td>
<td>46</td>
</tr>
<tr>
<td></td>
<td>(0.6)</td>
<td>(0.6)</td>
<td>(1:1)</td>
<td>(21)</td>
</tr>
<tr>
<td>PPM-DOTS clinic, Hyderabad</td>
<td>290</td>
<td>260</td>
<td>1:0.9</td>
<td>257</td>
</tr>
<tr>
<td></td>
<td>(89)</td>
<td>(83)</td>
<td>(1:0.9)</td>
<td>(33)</td>
</tr>
<tr>
<td>Govt. clinic, Hyderabad</td>
<td>8022</td>
<td>13591</td>
<td>1:1.7</td>
<td>1553</td>
</tr>
<tr>
<td></td>
<td>(64)</td>
<td>(34)</td>
<td>(1:0.5)</td>
<td>(8)</td>
</tr>
<tr>
<td>NGO clinic, Gujarat</td>
<td>22502</td>
<td>27838</td>
<td>1:1.2</td>
<td>319</td>
</tr>
<tr>
<td></td>
<td>(1.4)</td>
<td>(0.2)</td>
<td>(1:0.9)</td>
<td>(12)</td>
</tr>
<tr>
<td>BRAC centres, Bangladesh</td>
<td>612</td>
<td>304</td>
<td>1:0.5</td>
<td>63</td>
</tr>
<tr>
<td></td>
<td>(10)</td>
<td>(7)</td>
<td>(1:0.7)</td>
<td>(10)</td>
</tr>
</tbody>
</table>

a. M:F ratio calculated on actual numbers
b. Figures in parenthesis indicate percentage of column 1 or 2 as applicable.
c. Figures in parenthesis indicate ratio of percentages in column 3
d. M:F ratio calculated on actual figures. Ratios in parenthesis calculated on percentages

On the contrary, in the PPM project in Hyderabad, there was hardly any difference between sex-ratios among those presenting to TB clinic and those given a sputum examination (M:F: 1:0.9 and 1:0.8 respectively). It was difficult to know how much of the disparity was due to all doctors of the Gujarat NGO being males and the doctor at the PPM project’s clinic being a female. Some of the reasons why women are not subjected to sputum examination to the same extent as men could be as follows: selection biases on the part of providers; women presenting more often than men with unproductive cough and hence being unable to produce sputum for examination; the strong association between sputum exam and TB against the background of stigma prevalent in society; the prevalent perception that X-ray is the most appropriate test for TB which may lead some patients to leave the formal programme and seek an X-ray diagnosis; non-acceptance of diagnosis by patients and shopping for alternative diagnoses; problems of access to TB diagnosis and access to resources and support to reach these facilities.

Stigma, as a factor affecting women TB patients disproportionately has been reported by several studies. Help seeking behaviour of people, especially of women, may be influenced
by stigma, by making them reluctant to get their sputa examined and shop for diagnosis and treatment, often in places away from their residence [22,47,50,51]. Though the programme managers at BRAC feel stigma towards TB is a significant problem for women, the village-based female health volunteers feel that the levels of stigma have come down considerably over time, particularly since TB is now understood to be a curable disease and that free, good quality TB treatment is available in the village. During our discussions with patients we came across a woman who, after an unsuccessful visit to a private doctor for treatment for her cough, had been recognised by the female volunteer as a chest symptomatic and advised to attend the BRAC health centre for investigations. The patient followed this advice and was investigated, diagnosed and started on treatment in a fortnight’s time. All this was accomplished while her husband was away from home. However it is worth noting that this woman did not feel the need to hide the disease from her husband. Moreover, she felt she could depend on the BRAC volunteer to help inform and counsel him about her disease and its treatment.

Screening of patients for sputum examination and quality of sputum microscopy are two factors known to influence sputum positivity rate. An evaluation of the NTP in India showed that while the average number of sputum examinations in the peripheral health institutions had increased fourfold in a five-year period, the case rate (sputum positivity rate) had reduced to one half [47]. This could disproportionally affect women. A recent study of sputum microscopy in four African countries revealed that the probability of finding tubercle bacilli was less among women suspects than among men, the effect becoming more pronounced with increase in the age of persons with chest symptoms. The study suggested that women may have a higher prevalence of non-specific respiratory symptoms than men and that the prevalence of such conditions increases with increasing age [52]. This confirmed the findings of an earlier survey in India which showed the prevalence of sputum positivity to be higher in male symptomatics compared to female symptomatics, and higher among urban compared to rural areas [36]. It was believed that these results reflected differences in availability of information and access to health care in urban and rural areas, suggesting that better access to health care could in itself act as a screening mechanism among symptomatics. The possible reasons for low sputum positivity among women TB patients is another area for investigation. These reasons may range from poor explanation of sputum production techniques, more women having paucibacillary disease and non-
productive cough, cultural inhibitions against forcing up expectoration, or genuine inability to produce good quality sputum leading to submission of saliva.

Three of the centres we visited had higher sputum positivity rates among women compared to men. A common possible explanation was pre-screening of patients by some providers leading to a kind of selection. None of these places was giving a sputum examination to all patients with a cough of long duration. In the PPM project in Hyderabad, patients underwent two levels of screening – once by the referring private doctor and subsequently by the doctor at the TB clinic. In the NGO clinic in rural Gujarat, doctors used their own screening criteria resulting in a significantly fewer women being given a sputum test. The third centre which showed higher positivity among women was the government health centre in Bangladesh. Here too, patients often approached public health centres only after visiting one or more private providers. Delayed help seeking by women and issues of access may also be responsible for high sputum positivity among women.

4.6 TB treatment and outcome
(Barriers 4,5,6, Columns E,F,G)

Emerging from data not only from the field-sites but also from the NTPs of the three countries we visited, the sex and age structure of TB patients present a pattern [Table 3,4]. The overall M:F ratio for all three countries is 1:0.4, which is very closely reflected in the various centres for which data was collected, except the private trust hospital. For the 0 to 14 age group, all countries show an excess of females over males. This is in accordance with the known disease prevalence for that age group based on epidemiological surveys. For the 5-24 age group, the three urban sites we visited had varying sex ratios. In the two public health services, there were more males than females (M:F :: 1:0.8 and 1:0.6) while at the only private site, females outnumbered males (M:F::1:1.1). The rural sites also showed a low sex-ratio for this group suggesting that women in this age group who are usually young unmarried or newly married girls, tend to avoid public health services and go to the private sector. This would also explain the excess of females in this age group at the private facility where most patients are referred by private practitioners. In all the sites and the three NTPs, there is a gradual reduction in the proportion of total patients above the age of 15 who are female.
### Table 3: Age-wise distribution of New Smear Positive Cases

<table>
<thead>
<tr>
<th>Age group</th>
<th>Bangladesh NTP – 98 (First three quarters)</th>
<th>India RNTP – 93-95</th>
<th>Nepal NTP– 97-98</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>F</td>
<td>M:F</td>
</tr>
<tr>
<td>0-14</td>
<td>130</td>
<td>230</td>
<td>1:1.8</td>
</tr>
<tr>
<td>15-24</td>
<td>1849</td>
<td>1428</td>
<td>1:0.8</td>
</tr>
<tr>
<td>25-34</td>
<td>3385</td>
<td>1932</td>
<td>1:0.6</td>
</tr>
<tr>
<td>35-44</td>
<td>3639</td>
<td>1275</td>
<td>1:0.4</td>
</tr>
<tr>
<td>45-54</td>
<td>2834</td>
<td>732</td>
<td>1:0.3</td>
</tr>
<tr>
<td>55-64</td>
<td>2073</td>
<td>390</td>
<td>1:0.2</td>
</tr>
<tr>
<td>65+</td>
<td>1575</td>
<td>184</td>
<td>1:0.1</td>
</tr>
<tr>
<td>All ages</td>
<td>15485</td>
<td>6171</td>
<td>1:0.4</td>
</tr>
</tbody>
</table>

### Table 4: Age-wise distribution of New Smear Positive Cases in Visited Sites

<table>
<thead>
<tr>
<th>Age group</th>
<th>Govt. Hospital, Nepal (urban)</th>
<th>PPM-DOTS Hyderbad (urban)</th>
<th>Govt. of AP Hyderabad (urban)</th>
<th>Govt. of AP Medak (rural)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-14</td>
<td>3</td>
<td>16</td>
<td>1:5.3</td>
<td>2</td>
</tr>
<tr>
<td>15-24</td>
<td>106</td>
<td>82</td>
<td>1:0.8</td>
<td>31</td>
</tr>
<tr>
<td>25-34</td>
<td>60</td>
<td>22</td>
<td>1:0.4</td>
<td>22</td>
</tr>
<tr>
<td>35-44</td>
<td>51</td>
<td>14</td>
<td>1:0.3</td>
<td>13</td>
</tr>
<tr>
<td>45-54</td>
<td>48</td>
<td>10</td>
<td>1:0.5</td>
<td>11</td>
</tr>
<tr>
<td>55-64</td>
<td>28</td>
<td>2</td>
<td>1:0.1</td>
<td>7</td>
</tr>
<tr>
<td>65+</td>
<td>16</td>
<td>6</td>
<td>1:0.4</td>
<td>5</td>
</tr>
<tr>
<td>All ages</td>
<td>312</td>
<td>152</td>
<td>1:0.5</td>
<td>91</td>
</tr>
</tbody>
</table>
Where fewer women than men sputum positives are started on treatment initial default may be a factor. Initial defaulters are those who undergo sputum examination, are reported as positive, but do not return to make drug collections. The NTP in India reports the extent of initial defaulters to be around 5%, but these data are not disaggregated by sex [48]. Studies suggest that patients drop out of the programme at public facilities because of the widespread lack of confidence in the services provided, shortages of drugs and supplies, absence of staff and poor infrastructural facilities. The quality of medicines which are provided free of cost may be viewed as inferior by patients. Patients may also refuse treatment because of the inconvenience of frequently reporting to clinics with inconvenient opening hours situated far from their homes [22,47,53].

Providers may also apply selection criteria before starting patients on treatment. The research from Delhi referred to above showed that providers denied short course chemotherapy to 69% of the patients presenting for care because these patients did not fit the, informally developed, selection criteria [53]. Believing these patients to be likely to default for a variety of reasons, the functionaries feared that including them in the DOTS programme would bring the cure rates down thus reflecting badly on their performance. The patients denied entry into the programme tended to be among the most poor and the marginalised in their communities.

Treatment adherence or “compliance to treatment” is an aspect which has received a lot of attention in TB research but few studies have looked at the gender differentials in non-adherence to treatment. In one study, the reasons for inability to adhere to treatment have been reported to be different for men and women – while men dropped out due to pressures to return to wage work or due to alcohol and drug addiction, women dropped out because of the pressures of housework and the strain of keeping their condition secret [51].

Other studies indicate that men default more than women and that the rates of default are higher in the older (45+) age group [54,55,56,57,58,59]. A reliable predictor of default/drop out based on drug collection pattern has been reported to be defaulting in the first month of treatment [60]. An international review of articles and meta-analysis on compliance confirms that women are generally more likely to comply with TB treatment than men [61]. Despite the fact that factors which determine compliance – personal and cultural, operational and
institutional, structural and environmental – tend to work against women, they are nevertheless, more compliant. According to one view, this is because barriers to diagnosis of TB screen out the women who were the most likely to default, and those who make it to diagnosis and treatment are the ones most likely to have the necessary support and access to resources to complete treatment [22].

4.7 Socio-economic impact and mortality

Anecdotal evidence and qualitative studies based on small samples often fail to adequately convince policy makers of the social and economic impact of TB on women patients and on their families. A recent study revealed that having contracted TB, 15 per cent of female patients – rural and urban – faced rejection by their families, 11 per cent of school going children of women TB patients discontinued studies and an additional 8 per cent took up employment to support the family [Rajeshwari].

Tuberculosis is a leading killer of women of reproductive age worldwide. In the absence of chemotherapy, studies analysing mortality due to TB indicate higher mortality than their male counterparts among young to early-middle-aged women. An old study from Massachusetts and later studies from India and China show, that after around 30 years of age, men’s mortality rates are several times higher. It is explained in part by the higher rate of progression from infection to disease and partly by a higher case-fatality rate among women of these ages [18,20]. Among those who receive treatment, mortality is generally lower among women. [Borgdorff et al].

4.8 The continuum of gender disparity

Based on the foregoing analysis, it is possible to construct a generalised picture describing the experiences of a poor man and a poor woman, living in a poor country and suffering from symptoms of pulmonary tuberculosis. Burdened by the demands of daily survival, both the woman and the man will effectively ignore the mild, early symptoms of TB. Poorer access to resources might make the woman live with the suffering for a longer period than the man. Knowing the time and energy they will have to spend approaching the public health centre, which anyway is not very popular, they will often borrow money and visit a nearby private practitioner of some kind. Unrelieved, the man will make a few more visits to the private practitioner before ending up in the public health centre. Sensing that her disease might be
TB, however, the woman may either succeed in getting support from the family and seek care in private, mostly intermittently, where the confidentiality of her diagnosis will be maintained. If she is married she may get sent away by her in-laws to be cared for in her father’s home. Yet even if she is able to approach a health care provider, she is less likely to be suspected of having TB, is less likely to be given a sputum examination, and is less likely to be found sputum positive than the man. Away from her husband’s place, she may take treatment at a private or a public health centre and will generally follow the care giver’s advice more assiduously than the man. If the treatment provision is regular, she is more likely to complete the prescribed course of treatment, despite difficulties. If not, she is more likely to die of the disease than her male counterpart.

5. Towards a Strategy for research and action

The importance of addressing the root cause of gender disparities — poverty and poverty among women in particular — cannot be overemphasised. Empowering poor women with easy and equitable access to knowledge and resources on a sustainable basis may effectively address gender disparities but effecting these widely may not quite be expected or seen to be within the ambit of TB programmes at international, national or even local levels. A gender approach to TB at the policy level can only help inch towards the higher goal. The short term and medium term objectives of any strategy have to be focused on first making the various elements of the TB programmes gender sensitive. To enable this, the magnitude of gender-disparities in TB — from contracting the disease to obtaining cure — will have to be known, why and the extent to which the reasons for such disparities are biological, social or operational need to be investigated. There is no denying the need to undertake clinical and biomedical research on TB among women. Young women may have an altered immune function which may differentially influence their vulnerability to tuberculous infection, the symptoms they develop, their radiological patterns, their sputum positivity rates, disease progression, drug tolerance, and case fatality rates. There is also need for a better understanding of TB during pregnancy. The research strategy outlined here is restricted to operational aspects of TB control with regard to gender differentials.

The logical early steps to assess and address the impact of gender on TB control would be:
1. Assess the magnitude of the problem
2. Study gender differentials and
3. Pilot interventions to address the problems identified

For each of these steps, there could be two major components:

A. aimed at investigating and better understanding issues that cut across regions. WHO and international agencies should be better placed to address these. And

B. for guiding local programmes to examine and address gender disparities.

These are described below:
### 5.1 Assessing the magnitude

<table>
<thead>
<tr>
<th>A. Global</th>
<th>B. Local</th>
</tr>
</thead>
<tbody>
<tr>
<td>A clear understanding of gender differences in the epidemiology of TB will provide a sound basis for grasping the overall gender inequalities in TB and its control. Age and sex disaggregated analysis and cross-country comparisons of gender differentials from available population-based epidemiological data could be a first step to assess the magnitude of the problem, understand variations between and within regions and try to seek explanations for these. This has been done in part [18,20]. Problems of comparability of data and limitations of drawing conclusions that remain valid from dated surveys may partly restrict their utility. To be able to address whether less female notification is a result of deficiencies in notification, biological protection, or constraints of access, new, carefully designed surveys will have to be undertaken incorporating a gender perspective that has been absent in old surveys. We know that only half of those who develop TB worldwide are reported to the WHO [62]. The country with the highest burden – India – also has the largest private sector, which is often preferred for TB care by young women. And cases of TB in the private sector are not notified. It may be worthwhile to assess sex ratios among patients being treated in the private sector(s) and compare it with the local public sector. Data on sex ratios of notified pulmonary TB patients, sputum positives in particular, is available. This group is most important from the public health and TB control points of view. It will be useful also to examine sex-ratios among cases of sputum-negative and extrapulmonary TB.</td>
<td></td>
</tr>
<tr>
<td>Clearly, for a NTP or a district TB programme, three priority questions will have to be addressed as a starting point:</td>
<td></td>
</tr>
<tr>
<td>1. What is the sex-ratio among registered patients?</td>
<td></td>
</tr>
<tr>
<td>2. Are sputum positive females being missed out, to what extent, and which age group?</td>
<td></td>
</tr>
<tr>
<td>3. How do the treatment outcomes of female patients compare with their male counterparts?</td>
<td></td>
</tr>
<tr>
<td>This will give an idea not only of whether female patients within the programme are facing any constraints in completing their treatments, but also of the possible untapped load of female patients. This information may be derived from routinely collected records and will help sensitise the programme managers to start thinking from a gender perspective. Columns 5, 6, 7 and 8 of the conceptual framework represent this information. The sex ratios among sputum negative and extrapulmonary TB cases may also be determined within local programmes as a subsequent step.</td>
<td></td>
</tr>
</tbody>
</table>
5.2 Studying gender differentials

A. Global
In order to understand whether and if so, to what extent sex and age variations are due to biological or sociological factors (or a combination of both) a re-examination of existing data needs to be undertaken in conjunction with the collection of new evidence. But knowledge of sex ratios alone will not reveal the causes of gender differentials. Some basic questions remain unanswered and may be addressed through interdisciplinary research. Why are more males than females infected with M. tuberculosis, and why is this restricted to above the age of 15 years? Why do women of reproductive age have a greater risk of progressing from infection to clinical disease? Why are more males than females diagnosed with TB? The conceptual framework presented above may be helpful for this purpose. A common protocol now needs to be prepared incorporating epidemiological and social science methods to determine sex ratios and gender differentials at each stage during the course of the disease. This, if applied to different sites in different settings, will help delineate the commonalties of issues and interventions that may be required to be put in place across the sites. The outcome from each site will not only help identify appropriate interventions primarily relevant to the country and the region, but pooling of results will also facilitate the design of effective, widely applicable approaches and interventions.

B. Local
For a local TB programme, if sex-ratios among sputum positives reveal gross under-detection of women patients, it may be because of low positivity rates among women, fewer women being given a sputum examination or fewer women symptomatics seeking help from the programme. This may be ascertained simply from laboratory and out-patients registers. Columns 3 and 4 of the conceptual framework represent this information. Depending upon preliminary findings obtained from inserting appropriate figures into the bar chart, a study could be designed using quantitative and qualitative methods to determine the causes of the gender differences and to help design locally specific interventions to minimise these differences.
## 5.3 Piloting interventions

<table>
<thead>
<tr>
<th><strong>A. Global</strong></th>
<th><strong>B. Local</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>General guidelines to make TB programmes gender-sensitive should be based on the outcome of multi-centre operational research where interventions developed and adapted locally on the basis of the outcome of a well-designed protocol are applied on a pilot basis. Several different interventions may emerge, some general and applicable to all sites and some adapted to specific sites. And these may be a mix of technical, social, economic and operational interventions ranging from modifying criteria for screening of women symptomatics, helping women to bring up good quality sputa, appropriately altering diagnostic criteria, adapting methods of direct observation, giving educational messages aimed at women suspects and patients, sensitising health personnel to the gender dimension, posting female health care providers, offering monetary help to women towards travel and loss of wages, assessing the burden of women TB patients in the private sector and providing a conduit for those not affording private care to use improved public TB care services, relocating TB clinics to suit women patients' convenience, offering community-based care or integrating TB care within general and reproductive health care services. A package of commonly agreed interventions may be piloted and results analysed to arrive at an appropriate &quot;gender policy, strategy, and interventions&quot; for TB control.</td>
<td>By generating information to address specific questions emerging from an application of the bar diagram, a local programme should be better able to identify, design and implement interventions to rectify imbalances. The quick review of the Gujarat NGO showed beyond doubt that there was a provider bias against giving a sputum examination to women suspects and demonstrated an urgent need to discuss the bias with the doctors and standardise procedures. Low sputum positivity among females in all except one programme we visited prompted an investigation to determine the cause of the problem and if possible, correct it. The need to survey private providers and find out if it is they who are managing &quot;missing&quot; women TB patients was evident in BRAC. Analysis of data from the PPM project in Hyderabad revealed that the main source of a large number of their women patients were the female private practitioners in the vicinity, and indicated an opportunity to research into the effect of the sex of a health care provider on TB diagnosis and treatment. This programme also had a high number of young women patients being referred by the private sector and a prominent under representation of older women raising a further question. In Nepal, from where the isolated example of active case finding yielding more female patients has been documented, local researchers felt that the study needs to be replicated at several places and the findings reconfirmed, since it may have important implications for TB control programmes all over.</td>
</tr>
</tbody>
</table>
5.4 Making gender a process indicator

Total elimination of TB can only be a distant goal for TB programmes in poor economies. An achievable aim could be to attempt to strengthen the programme and improve its efficiency enough to be able to identify and cure TB among the poorest of the poor. Since a large proportion of the poor anywhere happen to be women, progress towards this goal may be reflected in and measured by reduction in gender disparities in finding, treating, holding and curing patients of TB. The benefits of curing a woman of TB are enormous; not just to herself, her husband and her other adult contacts but also extend beyond a generation by protecting her children. Similarly, the losses of leaving a good proportion of women out of TB programmes, as appears to be happening now, would also be enormous to those women, their families and communities. An index of gender disparity may therefore make a useful process indicator to gauge progress of TB programmes in the desired direction. This may well apply also to other disease control programmes and health and development in general.

5.5 Early steps

In summary, the following steps may constitute a purposeful beginning towards identifying gender related gaps and weaknesses in the current TB control interventions and help devise and implement measures to minimise them.

a. Re-examination and age and sex-disaggregated analyses of select information available and accessible globally, to assess the magnitude and characteristics of and variation in gender disparities.

b. Development of a standard protocol incorporating epidemiological and social science methods, to identify reasons and interventions for gender disparities within TB programmes at multiple sites.

c. Application of the standard protocol to multiple sites with varying sex-ratios with the objectives of identifying gender differentials, pooling of results, and designing a package of appropriate interventions.

d. Piloting interventions – general and local – identified and adapted on the basis of application of a standard protocol to multiple sites.

e. Development of “standard guidelines and tools” for recording and reporting the minimum required gender-related information within ongoing programmes for current and future use.
f. Undertaking population based surveys to determine reasons for low female notifications and to assess the extent of biological protection, incorporating a component of immunological research.

g. Setting-up an interdisciplinary gender research group cutting across programmes and clusters to promote exchange of information among diverse disciplines, and to develop and pursue a broad agenda for gender-sensitive research and intervention in health and development.

It must be stressed that TB programme managers should not wait for the long-winded process of undertaking research and translating it into policy and practice, to be completed. The strategy outlined above has several elements applicable to ongoing programmes for which a re-view rather than new research is what will be required. In fact, by taking initiatives to make their programmes gender-sensitive, programme managers may meaningfully contribute to development and implementation of a global action-research strategy. As elsewhere, in operational research too, a bottom-up approach is likely to be more participatory and productive.

To conclude, this paper highlights a number of gaps in our knowledge around the effects of sex and gender on tuberculosis control and possible ways to address it. Research and knowledge generation to fill known gaps needs to take place at the international, national and local levels. As outlined in the strategy, international research should focus on generating data, which is likely to cut across regional and cultural contexts. International donors should encourage comparative research to identify the common threads across contexts, biological and sociological, which can be used to inform a gender approach to tuberculosis policy. At the national and local levels further research needs to be undertaken which relates to the performance and overall gender-sensitivity of individual programmes.

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References


