Tuberculosis and Gender

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Abstract:

Tuberculosis (TB) kills about one million women per year and it is estimated that almost one billion women and girls are infected with TB. Gender aspects of tuberculosis has been a neglected research area, and little attention has been given to these aspects of tuberculosis control. This review brings forward publications on gender and TB and illuminates areas where gender has an impact on the disease and its control. The authors use a conceptual frame work for the purpose of identifying gender related issues and research questions within the development from infection by M tuberculosis to TB disease. Important findings from within authors' research group are presented and discussed, using Vietnam as a case study. Studies from Vietnam have shown that women with pulmonary TB are diagnosed on average two weeks later than men, due to a delay from the health care provider, and in a study on cough patients it was found that men more often than women were asked for a sputum specimen. Negative social consequences have been shown to be more of importance to women, and stigma is still associated with TB disease. The review aims at showing how biological and social factors in many contexts interact in creating an unfavourable situation for women regarding possibilities of TB diagnosis, treatment and cure.
Tuberculosis (TB) is one of the major public health problems globally (WHO 2000) and since 1993 the WHO has declared TB a global emergency. To face this emergency the WHO has developed a policy and strategy - Direct Observed Therapy Short Course (DOTS). The WHO is forcefully pushing for this strategy with particular concern for the development of multi-drug resistant TB globally. The policy has many positive aspects and is considered efficient and cost effective. However, the policy is not gender sensitive and does not take into consideration the different life conditions affecting men and women in the world.

Ninety five percent of TB cases and 98% of TB deaths takes place in low and middle-income countries (WHO 2000). Poverty and TB are strongly related. Positive health development, including the progressive reduction of TB, in today’s rich industrialised countries has followed the economic and social development in these countries. This fact is ignored in the present policy of TB control by WHO. Moreover, the present programme strategy is based on the experience of countries with continuous and significant economic growth during the period 1900 – 1970, the period when TB incidence and mortality decreased considerably. The countries facing the biggest challenge of TB today are poor and in many countries (particularly in sub-Saharan Africa), economic growth is stagnant. In situations of poverty, life conditions of both men and women expose them to health hazards including the risk of TB. Poverty exaggerates the gender differences with negative health implications for the partner with the least power. These implications include the risk of infection and development of disease, access to care and cure from TB. A reason why the WHO’s present strategy is not gender sensitive is that only limited information is available on how the different life conditions and biology of males and females affect the risk of infection, progression to disease, case fatality and access to care and cure from TB. This paper is based on the available literature as well as on our own research on gender and TB.

Conceptual framework for the analysis of gender differences in tuberculosis

Infectious diseases in general and TB in particular could be seen as a process following the chain of events starting from exposure to infection, to development of disease, to individuals and communities efforts to find a cure. At each of the steps
there are gender-related factors which influence the care and cure of men and women. In figure 1, these steps are presented and gender-related questions are identified.
Figure 1. Conceptual framework and research questions for gender and tuberculosis research

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Source: [Long NH, 2000]
Epidemiology and biology of Tuberculosis

TB incidence and notification-rates
During the last decades, TB has been known to western societies as “the old man’s friend”, despite the strikingly high incidences among the productive age groups in low-income countries. Still, the concept of regarding TB as primarily a male disease has some bearing in light of the global notification rates regularly collected by the WHO. The male to female ratio of TB cases reported to the WHO is around 1.5-2.1 in all regions of the world (WHO 2000). The male-female estimated age specific incidence curves and the ratio between male-female cases are visualised in figure 2. Studying the age specific notification rates reveals that the gap between male and female reported cases seems to start after puberty. The peak ages for the respective rates vary between the different regions, and also the magnitude of the difference between reported cases.
Figure 2 Estimated sex-specific incidence rates 1998

Incidence Rates by Age and Sex:

Sub-Saharan Africa, 1998

Incidence Rates by Age and Sex:

South-East Asia, 1998
Incidence Rates by Age and Sex:

Industrialized countries, 1998

Source: WHO Global Tuberculosis report, 2000
The ratings from different regions create a pattern of male excess, but no clear explanation to this finding has been presented. It seems probable that a combination of different factors such as biological differences in disease and disease presentation, together with gender related factors like access to health care may be part of the explanation. Thus it is not known whether this is a genuine difference in incidence, the result of an underreporting of female cases, or a combination of both.

What is even more intriguing is the different pattern of sex specific notification rates that was common during the early and middle of the 20\textsuperscript{th} century in the northern European countries. Data from these countries were examined for gender differences in a review from 1998 (Holmes CB 1998). In Denmark (1939-41), Norway (1937), England and Wales (1952-54) notification rates were similar for both sexes below age 15 but higher among women until their mid-twenties or early thirties. After age 40 notification rates were higher for men in most of these countries. Similar results were seen in an epidemiological study in Denmark carried out as a follow up to the Danish mass campaign in the 1950s (Holmes CB 1998). Thus data from these countries, which had at the time equally or even higher notification rates than in the low-income countries today, show a sex-reversed pattern.

The WHO control strategy of TB, “DOTS”, adopted in 1998 by 119 countries (WHO 2000), promotes passive case finding of pulmonary, contagious cases of TB. The concept of “passive” refers to the role of the health care provider/TB programme that thus does not actively screen the population of TB, but instead awaits the initiative of the sick person. This model has been proved cost-effective from a public health perspective. However, for the purpose of investigating a possible under-notification of female and male cases the resource-consuming model of active case finding is better suited. Few such studies exist, but during the 20\textsuperscript{th} century in many of the Eastern European countries active case finding was common. In the previously mentioned review one has found a study from Czechoslovakia in the sixties that compared two years of active case finding with two years of passive detection. It was found that men had twice as high recorded incidence as women during the years of passive case finding, but when subject to active screening incidence rates were similar between sexes. Similarly a study carried out in Eastern Nepal in the early eighties that compared active with passive case detection showed interesting results. When using
active case finding 46% of the detected cases were females, compared to the group who had to refer themselves to health care, which consisted of only 28% females (Cassels A, 1982).

Against possible female under-notification based on a barrier to health care access is the evidence from a retrospective study of age- and sex-specific TB prevalence rates of smear-positive TB, compared to age and sex-specific notification rates (Borgdorff MW, 2000). The study did not find any evidence for male-female differences in detection rates being caused by impaired access to health care for women, and interpreted differences in notification rates as differences in actual incidences of TB. Still, due to methodological weaknesses it is not possible to derive conclusive evidence from this study. The African prevalence studies used were carried out many years before the notification rates, and some of the included prevalence studies had small sample sizes. The validity of estimating prevalence by sputum testing is based on assumptions of a similar sensitivity of sputum testing in men and women, and a similar duration of sputum positivity among men and women. If there were indeed sex dependent differences in these parameters, the results from prevalence surveys based on sputum testing would be invalid for determining sex or gender differences.

The studies above illuminate how the female gender role and the related power structure is in some contexts linked to barriers to health care access. There is also another possible mean of creating under-notification of female cases attributable to the health care providers. There is a need to investigate how they act to reproduce old beliefs about the disease and create meanings of gender in relation to patients.

In a population-based study of patients with a cough for more than 3 weeks in Vietnam we found that among men and women who sought hospital care, significantly more men than women were asked to provide a sputum specimen for TB diagnosis (Thorson A 2000). This was shown despite the fact that no differences in other symptoms or cough duration were found between the groups. Johansson has described how the interaction between a male doctor and female patient could be characterised by lack of communication and presumptions that may impair the outcome of the consultation (Johansson E, 2000). In another study in Vietnam, the diagnostic delays in a patient cohort of 1,027 new smear-positive pulmonary TB
patients were studied (Long NH 1999). It was found that the patient’s delay was similar for men and women, whereas both the health care provider’s delay and doctor’s delay were significantly longer for women. The mean delay to diagnosis was found to be about two weeks longer for women, thus possibly indicating a failure of the health care system in diagnosing women with sputum positive TB. Given these examples it seems that female suspected TB patients may be at risk of not getting adequate diagnostic investigations, on the basis of no other characteristics than their sex.

Existing evidence also suggests that there may be biological differences in symptom presenting between male and female TB patients. The previously mentioned study from Vietnam showed that at the time of diagnosis fewer women reported each of the symptoms of cough, sputum production or hemoptysis. At follow up after one month, significantly more women than men had recovered from their symptoms of cough and sputum production (Long NH, 2000). Studies that indicate sex-specific differences in the severity and localisation of lung lesions could correspond to differences in symptoms and symptom recovery. The WHO recommends sputum testing to be carried out in all patients who present with a cough for more than three weeks, especially with sputum production or hemoptysis. In low-income settings case detection relies mainly on the physicians’ ability to recognise patients with these symptoms. If there are sex differences in how and what symptoms are presented, and differences in the sensitivity of sputum testing, the assumption that male symptoms and characteristics are normative may have an adverse effect not only on the individual TB patient, but also to public health. It could also be concluded that the reported notification rates of TB in some contexts may not reflect the actual TB incidence, but instead a gender biased estimate.

Another issue seldom discussed is the fact that global TB control strategies primarily focus on pulmonary, contagious TB. This is, of course, the form of disease that is most important to public health. However, TB represents many different forms and clinical manifestations. In a large study on extra-pulmonary TB it was found that more women than men were diagnosed with extra-pulmonary forms of TB (Bothamley G, 1998). In separate studies on TB in different organ systems other than the lungs, women were found to get these diagnoses at least as often as men do. Thus
a strong focus on the prevention and treatment of pulmonary, contagious TB may lead to a situation in which the diffuse, "atypical" symptoms of extra-pulmonary TB are less often recognised by patients, and also by health care providers. This is an area where female sex again may create a disadvantaged situation for women, but where very little is yet known about the actual consequences for women and men.

**Tuberculosis infection**

Infection with *Mycobacterium tuberculosis* starts a complicated immune response in the infected human. The most common method of investigating the prevalence of TB infection is through tuberculin testing, i.e. measuring the skin-reaction to a specific injected substance and the subsequent immune response to the injection.

An analysis of tuberculin surveys around the world during 1948-1951 showed that the prevalence of infection was equal between males and females during childhood, and that between 10 and 16 years of age male prevalence began to exceed that of female (Holmes CB, 1998). Similar results on the prevalence are reported from prevalence surveys in Africa, India and Korea (Figure 3) (Dolin P, 1998). A theory that is often presented as an explanation to the sex differences is that men in general have a wider social net-work that would lead to a greater exposure to the Mycobacteria. This difference in social contacts is considered to be of importance after puberty, following the differentiation into gender roles. However, the possible variations in social habits of men and women in different cultural contexts seem too large to enable explanations of similarities in global prevalence patterns.
Figure 3. Prevalence of tuberculosis infection by sex and age group (Dolin, 1998).
Another explanation could be if tuberculin testing has a different sensitivity in men and women, caused by differences in the immune response to TB infection. This hypothesis is supported by a study from Japan showing that more males than female TB patients had a positive tuberculin reaction (Kurosawa 1990). In a study of senior school children in Kuwait, boys were found to have a delayed type hypersensitivity reaction (i.e. the reaction to the tuberculin test) to more mycobacterial sensitins than girls, as well as larger scars after BCG revaccination (Shaaben MA 1990). These results are similar to what is commonly found in under-nourished or HIV positive populations, where the tuberculin test has a very low sensitivity for assessing TB infection, because of immune deficiency. The study results presented above indicate that tuberculin testing may also be less sensitive in women, due to differences in immune response compared to male subjects, and thus the results presented on prevalence and/or susceptibility to infection may suffer from a sex-bias. Research to address these theories has so far been scarce (Bothamley G, 1998).

**Progression from infection to disease and case fatality rate**

Tuberculosis is an immunologically complicated infectious disease, where only about 10% of those infected in a normal, non-HIV affected population, will ever develop the disease. It means also that a childhood infection may wait until late life before developing into active disease. In the review of epidemiological sex differences from 1998, studies on progression from infection to disease were also presented. A higher rate of progression from infection to disease among reproductive age women has been described in several studies (Holmes CB 1998). In a prospective study conducted in Bangalore, India (Olakowski T 1973) it was found that females had up to 130% higher risk of progressing from TB infection to disease between the ages of 10 and 44 years. In Puerto-Rico tuberculin positive individuals were followed for on average 18.7 years, and the progression to active TB (all forms) was 17% higher among women, the male rate was higher only in the one to six year age group (Comstock GW, 1973). Similar results have been shown in a study from Alaska and in several studies from high-income settings (Holmes CB 1998).
In the Bangalore study case fatality rate was examined and was found to be 27-41% higher for females aged 5-24 whereas the male/female ratio of case-fatality was similar after the age of 25. These findings are consistent results from a survey carried out in China (Ministry of Public Health, China 1985) in which women were found to have higher TB mortality rates from birth and through the age of 29.

Different explanations have been suggested to explain why women of reproductive age would have a higher progression from infection to active TB and also a higher case fatality rate. An argument questioning these findings has been that women are more likely to use health services during their reproductive years, and thus are more likely to be diagnosed with TB at this time in life. This argument does not explain the findings in the Bangalore study where active case finding was used, and it seems also too simplistic to generalise about the health seeking behaviour of women in these different contexts.

Instead one of the most common theories has been that the stresses of pregnancy affect the immune response, and thus promote the onset of disease. However, scientific studies have produced contradictory and inconclusive results on the relation between TB and pregnancy (Grange J, 1998). The hormonal and physiological changes during the post-partum period have also been discussed as possible risk factors to the progression to disease, but this relation has not been shown in scientific studies. In conclusion it may be stated that despite a relatively large number of studies carried out addressing this aspect of TB, the relation between pregnancy and progression to active TB disease or case fatality is not clear (Grange J 1998).

It is also noteworthy that albeit the inconclusive research results in this field, it is still one of the few fields where an interest in how TB affects women has been explored. The strong focus on TB and pregnancy, compared to the lack of interest in other aspects of the impact of TB in women, shows how research relating to gender issues has previously been reduced to an interest in effects on female reproduction. This focus is thus emphasising the societal view of women as having primary importance for their function as child bearers and caretakers. The spheres of women’s lives that do not include reproduction have been of marginal interest to the research world.
Gender specific social-cultural context of Tuberculosis and its effect on health care-seeking and compliance: A case study from Vietnam

Traditional and modern/scientific perceptions of TB, its treatment and control

Long et al. (1999) has described traditional beliefs in four main types of TB: (i) ‘Lao truyen’, perceived to be handed down ‘through the blood’ from generation to generation, to be non-contagious and believed to affect both men and women; (ii) ‘Lao luc’, perceived to be caused by hard work, to be non-contagious, more common in men than in women; (iii) ‘Lao tam’, perceived to be caused by ‘too much thinking’, non-contagious, more common among women than among men; and (iv) ‘Lao phoi’, perceived to be transmitted through the respiratory system, to be contagious and believed to be ‘the most dangerous type of TB’. It has further been described that TB traditionally was perceived to be a ‘dirty’, incurable and deadly disease (Johansson).

Current existence of traditional perceptions of TB might be explained by a strong Vietnamese family structure, characterised by strict hierarchy, where each member of the family occupies a certain position with precedence based on generation, age and sex. Elderly people, in particular women, have a strong influence on how to react and behave when illness affects the family (Bich, 1997). Therefore, it could be such that even if modern/scientific explanatory models are known to the young in a family, traditional beliefs still predominate in case of illness because of the influence that
elderly people have on family matters. To have co-existing traditional and modern/scientific perspectives on TB prevailing in the society is an aspect worth noting. Vietnam has a long history of traditional medicine, more recently also along with Western medicine. The two treatment traditions are, most of the time and in most situations, looked upon as complementary. However, in the case of TB, one must note the risks of a traditional approach to the disease, especially if it is combined with Western medicines. An example of this danger is the traditional belief in the four different types of TB, where it is believed that only one of the four traditional types of TB is related to the ‘germ theory’, which means that only one of the four types is looked upon as contagious (Long et al. 1999). This has implications for TB control and treatment in terms of increased risk of spreading the disease and also a belief that it is not necessary to treat the disease with anti-tuberculosis drugs in three of the four types. Similar traditional perceptions of TB have been described from other countries. Liefooghe et al. (1997) described from Kenya how TB was perceived as hereditary, handed down to later generations within the family. The disease has further been described in Pakistan (Liefooghe et al. 1995) and in the Philippines (Nichter, 1994) as a ‘family disease’ rather than one affecting the individual.

There is a need to note existing differences in perceptions and understanding of TB between people from different generations, of different sex, with varying education and living in different areas of the country in order to become aware of local variety. Women seemed to be more sensitive to traditional beliefs in the family/community than men and thus more prone to hiding the disease. If possible, TB control and treatment, in Vietnam as well as elsewhere, should be adjusted to local perceptions and understanding of TB and TB treatment.

**Family structure and status of individual family members**

Johansson (2000) has described how gender roles, status and support from the family have an influence on both health-care-seeking behaviour and compliance with treatment and thereby how the sickness trajectory develops, either in support of the treatment process or as a barrier to it. It is therefore of great importance for staff involved in TB treatment and care to be familiar with and understand the situation of each individual patient in order to be able to give adequate support to the patient and his/her family and to prevent non-compliance with treatment. Gender roles and status
of the patient in the family were strong determinants for the type and amount of support that was given to the TB patients by their families. Concerns of men and women also differed because of their different roles in family and society.

Empirical data (Johansson, 2000) further indicated that despite suffering from TB disease, men were supported and treated with respect by other family members, while women were sometimes threatened, humiliated and subjected to divorce. This has also been described by Liefooghe et al. (1995) from their research in Pakistan when women were subjected to divorce because of TB disease. Also Nair et al. (1997) has reported from India how women were concerned about rejection by husbands, harassment by in-laws and reduced chances of marriage, if single.

What consequences do gender roles have on health seeking behaviour and compliance with treatment and how can staff manage to prevent irrational and harmful behaviour among TB patients and their families as a consequence of traditional ways of looking at gender, and thereby the status of individual family members?

The context of the individual patient seemed to be of great importance for how the period of treatment developed, if treatment was interrupted or completed (Johansson et al. 1999; Johansson, 2000). The way people look at and value the status of various family members was, to a high degree, dependent on prevailing gender norms in a community. Reactions of family members towards a TB sick person were strongly influenced by the status the TB sick person possessed in the family. A man, especially if he was the head of family, was mostly well supported and treated with respect. Despite the disease, his status was seldom questioned or threatened. A woman, on the other hand, was at times left without support, rejected or even divorced.

The weak position of women in Vietnam had consequences such as denial and/or concealment of diagnosis of TB for fear of social isolation, harassment and divorce (Johansson et al. 2000; Johansson, 2000). It was further described how the weak position of women in their families created low self-esteem and a fear of talking. The strong position of the husband in the family, on the other hand, seemed to create self-esteem and a possibility to act on his own initiative without consulting the rest of the family; he did not become isolated in his family, he received all possible support and did not need to fear rejection or divorce. Social isolation would therefore have less impact on men than on women.
Fear of enacted stigma was the main concern for compliance with treatment among women, who described how they felt isolated by relatives and neighbours and how people no longer visited them or wanted ‘to have tea with them’ (Johansson et al.1999). Women further described how their situation and status in the family was influenced by the TB diagnosis and how TB sick women were less respected than TB sick men. Women appeared to be more isolated in their own families than men. Men did not describe any feeling of being isolated in their own family. Women also described how they isolated themselves from their family and community, indicative of felt stigma. Men did not seem to fear rejection by others or divorce in the same way as women. It is, however, possible that women actually were more isolated compared to men, but it might also be that impact of isolation itself was more pronounced in women than in men.

What can be done then, from the provider’s point of view, to improve services to the TB sick and their families, in particular, to female TB patients? Johansson (2000) found that staff need to inform themselves about each patient and his/her family, find out how much is understood of TB and TB treatment and what kind of support the family itself is prepared to give to the sick person (Johansson, 2000). Staff must be prepared to communicate with each patient and his/her family to make them understand how important it is to seek early health care and comply with treatment. There is a need to build up transparency (systematic meetings with patients and families) and trust between providers, patients and families.

Socio-economic factors and patients cost; a barrier to effective TB control and treatment?

Concerns of men and women in Vietnam have been described as different by Johansson (2000), often ascribed to their different roles in the family and society. Being dependent on husbands and in-laws, women feared rejection by husbands, other family members and society. By contrast, economic burden was the main concern of men throughout the health care-seeking process and treatment period. Many patients described how the costs of TB treatment exceeded their income and how treatment costs, although drugs are free of charge, remained a major concern and sometimes led to non-compliance with treatment. The only alternative for poor people was at times
to practice self-medication or to borrow money. The economic burden was greater
when the husband got the disease compared to the wife, as he usually generated the
major part of the family’s income. Some patients had to leave their jobs in order to get
a less strenuous job, often providing less income. Poverty acted as a barrier to both
adequate health care-seeking and to compliance with the full course of treatment. One
explanation to why men were more sensitive to economic difficulties than women
could be that most men are in the position of being the head of the family, the main
decision maker and the one who has the ultimate responsibility for the family’s
economic well-being. Another explanation could be that the economic burden of the
family increases more if the husband becomes ill than if the wife becomes ill as the
husband in most cases generates the major part of the family’s income. When TB
treatment is described as ‘free-of-charge’, costs of the individual patient and his/her
family are often neglected. Johansson et al. (2000) found in their studies how that
patient costs sometimes far exceeded the income and resources of the family and how
they were forced to borrow money to cover expenses during the treatment period –
loans that sometimes took years to pay back.

Stigma: a summary effect from contextual factors
In the studies of Johansson et al (1999) and (2000), stigma seemed to be a summary
effect of contextual factors mediated via denial and concealment of the disease. Both
phenomena seemed to be more common among women than among men and lead to
delay in health care-seeking and non-compliance with treatment. If TB, for example,
was perceived as a ‘dirty disease’ in a community, this might have stigmatising
implications in terms of delay in health care-seeking and possibly also non-
compliance with treatment.

A model of contextual influence on health care-seeking behaviour was developed by
Johansson et al (2000). The model shows how the context of TB relates to stigma,
mediated via denial and concealment of the disease, and actual health care-seeking
behaviour. Two types of delay were identified; patient’s delay and systems’ delay.
(Figure 5).
Two types of stigma were observed: one related directly to the patient him/herself, ‘felt stigma’ and another related to the surrounding family or community, ‘enacted stigma’. Goffman has defined stigma as an "attribute that is deeply discrediting, where enacted stigma refers to episodes of discrimination against people on the grounds of social unacceptability or inferiority and felt stigma is based on a deep sense of inferiority and refers to an oppressive fear of enacted stigma” (Goffman, 1968). Fear of enacted stigma was the main concern of women at suspicion of TB, in health care-seeking and in compliance with treatment. Women even isolated themselves because of felt stigma and for fear of enacted stigma. Men did not
demonstrate the same fear of enacted stigma (Johansson 2000). The main reactions to both felt and enacted stigma were denial and concealment of the disease leading to self-medication, delay in health care-seeking and interruption of treatment; these latter may in their turn lead to severe forms of TB, development of chronic cases, drug resistance and death.

**Interaction between patient/family and the health care system**

Several male doctors described a non-functioning communication between male doctors and female patients (Johansson, 2000). The doctors described consultations with female patients as ‘difficult’ and how women presented their symptoms in a ‘less concrete’ way. Female doctors reported no problems at all in examining or dealing with either male or female patients. The same study expresses the need for open, transparent and well-informed communication between the TB programme providers and the patients and their families. It is essential and required for the development of trust between the two parties and thus for forming a basis for mutual understanding and shared responsibilities. However, neither staff nor patients seemed to be conscious of the benefits of such a relationship. In particular, patients had difficulties in imagining a health care system containing such a policy component. Most interviewees did not seem to be accustomed to the role of being in control of or even influencing their own treatment when in contact with the health care system; on the other hand, control and influence were maintained through self-treatment. However, it appeared easier for men compared to women to be and remain in control of their own treatment process because of their higher status in the family and their possibility to better control their own situation. Poor communication seemed to exist between male doctors and female patients since female doctors did not report experiences of the same kind. It might of course reflect a general communication problem between male doctors and female patients, but nevertheless, it is a serious observation of significance for TB diagnosis and treatment since it may cause unnecessary delay in the diagnosis of women. The difficulty for male doctors to interact with female patients might contribute to explain the three weeks longer doctor’s delay for women reported by Long et al., (1999). Encounters took place between doctors and patients but encounters between doctors and the patients’ families rarely took place. It must be seen as important to initiate regular encounters between the doctor and family
members to facilitate necessary support for the patients, in particular female patients. Even if a female patient understood about TB, TB treatment and the curability of the disease, the other family members might not have understood, and therefore did not support the TB patient in a sufficient way. The role of TB staff therefore is crucial for educating family members.

Seeking cure: patient and health system related delays

Most countries in the world now apply passive case-finding approach for TB detection. The term “passive case-finding” used here describes such methods for the identification of TB cases where the initiative for an individual patient-health provider contact is taken by the patient (Rieder, 1993). As mentioned earlier, in most low and middle-income countries about two-thirds of reported TB cases are men and only one-third women (Figure 2), and it is not well known whether this is due to a higher risk of developing TB among men or under-notification of TB among women. Analysis of TB notification history suggests the possibility that cases of TB among women are being under-reported in developing regions (Holmes et al., 1998). Health care-seeking is a complex phenomena that could be effected by many factors (Puentes-Markides, 1992). In the following section, we will describe health seeking behaviour delays in TB diagnosis with special reference to differences between men and women.

There are a number of delays in health seeking and diagnosis of TB (Figure 5). (i) “Delay to first health provider” is the time interval from onset of symptoms to the first visit to any health care provider, including self-medication; (ii) “Patient’s delay” is the time interval from onset of symptoms to the first visit to a hospital or a doctor; (iii) “Doctor’s delay” is the time interval from the first visit to a hospital or a doctor to a TB diagnosis; (iv) “Total delay” is the time interval from onset of symptoms to a TB diagnosis. This can also be called “Total diagnostic delay”; (v) “Treatment delay” is the time interval from diagnosis to the start of treatment; (vi) “Total treatment delay” is the time interval from onset of symptoms until the start of treatment.

<table>
<thead>
<tr>
<th>Onset of symptoms</th>
<th>First health provider</th>
<th>Doctor or hospital</th>
<th>TB diagnosis</th>
<th>TB treatment</th>
</tr>
</thead>
</table>


The long delays to TB diagnosis have adverse effects on the patients, their family members, society, as well as TB control in general (Mathur et al., 1994). In a study in Sremska Mamenica, Zafran reported that delay in the detection of TB was the main factor contributing to the death of TB patients (Zafran et al., 1994). A study in Australia on diagnostic delay and transmission of TB in an office concluded that delay in diagnosis was the major factor responsible for the spread of TB in the studied office (MacIntyre et al., 1995). Long diagnostic delays among women have even more adverse effects as the health and welfare of children and other family members is closely linked to that of the mothers (Hudelson, 1996). Therefore, reducing delays in TB health seeking and diagnosis is especially important among women.

Both patient and doctors delay are important
Delays in health care-seeking and TB diagnosis have been addressed by a number of studies in different countries. Common range of the mean total diagnostic delays is 3-4 months (Table 1). The proportions of patient’s and doctor’s delays, respectively, among total delays are different between settings. Some studies reported that patient’s delays were longer than doctor’s delay (Mori et al., 1992, Wandwalo, 2000, Long et al., 1999), while others found doctor’s delays were longer (Beyers et al., 1994; Franco et al., 1996; Lawn et al., 1998).

Table 1. Delays in health-seeking of and tuberculosis diagnosis

| Place | Measurement | Patient’s delay | Doctor’s delay | Total delay |
|-------|-------------|-----------------|---------------|-------------|-------------|
|       |             |                 |               |             |             |
How gender influences delays in TB care-seeking

While many studies have addressed delays in TB health care-seeking in general, few have analysed gender differences in delays. Although studies report conflicting findings about differences between men and women in delays, the overall trend shows that delays to TB diagnosis for women are longer than for men. A study that interviewed 1,027 new smear-positive PTB patients in 4 provinces of Vietnam reported that the mean total delay was significantly longer among women (13.3 weeks) than among men (11.4 weeks). As the delay to first health care provider and patient’s delay were not significantly different between the two sexes, the difference between men and women in total delay was attributed to the significantly longer doctor’s delay for women (5.4 weeks) than for men (3.8 weeks) (Table 2) (Long et al., 1999).

**Table 2:** Delays in health care-seeking among 1027 new cases of sputum positive tuberculosis in four provinces in Vietnam.

<table>
<thead>
<tr>
<th>Delays</th>
<th>Total</th>
<th>Men (N=757)</th>
<th>Women (N=270)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total delay</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean (weeks)</td>
<td>11.9</td>
<td>11.4</td>
<td>13.3</td>
<td>0.02</td>
</tr>
</tbody>
</table>
95% CI of mean | (11.2-12.6) | (10.6-12.2) | (11.5-15.1)
---|---|---|---
Patient’s delay
Mean (weeks) | 7.7 | 7.6 | 7.9 | 0.71
95% CI of mean | (7.1-8.3) | (6.9-8.3) | (6.5-9.3)
Doctor’s delay
Mean (weeks) | 4.2 | 3.8 | 5.4 | 0.003
95% CI of mean | (3.9-4.5) | (3.3-4.3) | (4.2-6.6)
Delay to first health provider
Mean (weeks) | 5.8 | 5.9 | 5.6 | 0.65
95% CI of mean | (5.3-6.3) | (5.3-6.5) | (4.5-6.7)
Health care provider’s delay
Mean (weeks) | 6.1 | 5.5 | 7.7 | 0.003
95% CI of mean | 5.7-6.5 | 5.1-5.9 | 6.8-8.5
Source: Long et al., 1999.

A study on 100 adults with newly diagnosed smear-positive pulmonary TB in Ghana reported that delay in diagnosis of pulmonary TB was unacceptably high, and doctor’s delay was also significantly longer for women than for men (Lawn et al., 1998). Another study in Japan also reported that doctor’s delay was significantly longer for female than for male patients (Sasaki et al., 1996).

Two studies from Japan reported that total delay tended to be longer in men than in women (Niijima et al., 1990; Hooi, 1994), and there was a report of no gender-related difference in total delay in Australia (Pirkis et al., 1996). Perhaps this is a reflection of different gender roles in different societies and/or differences in TB diagnostic performance of health workers between the study settings.

A population-based study among people with a cough for more than 3 weeks reported that although women did not start seeking health care later than men, they often sought health care from less qualified providers, took more health care actions, and had longer delay to hospital than men (Thorson et al., 2000). Data from a qualitative study also supported that trend. The overall health-seeking pattern of men was described to mainly consist of a neglect of symptoms until a late stage of the disease,
then followed by a tendency to go straight to public health services, e.g., hospitals, without an initial visit to a private practitioner or an attempt at practising self-medication. Women were perceived to practise self-medication, visit a private health practitioner or a less-qualified health provider close to home first, then see hospital services (Johansson et al., 1999, Johansson, 2000). This pattern results in more health care visits before TB is diagnosed among women (Long et al., 1999).

Some other authors also reported similar findings. A study in Catalonia (Spain) reported that the proportion of women visiting a health professional was slightly greater than that for men, however, the proportion of hospitalisations was lower among women than among men (Fernandez et al., 1999).

**Why do women have a longer delay to TB diagnosis then men?**

In a passive case-detection approach the most important factors for early case-detection include early recognition of TB suggestive symptoms, early and adequate health care-seeking of the TB suspects, and appropriate diagnostic performance by the health workers. This process is influenced by three main groups of inter-related factors: (i) biological factors (occurrence of symptoms, severity of disease); (ii) health care system factors (availability of health care service, accessibility of service, quality of service); and (iii) socio-economic and cultural factors (poverty, social stigma, isolation, cultural behaviour and belief). Some of these factors are described in further detail bellow.

**Biological factors**

According to the guidelines of the WHO Global TB Control and IUATLD, the most important suggestive symptom for pulmonary TB is a cough for more than 3 weeks (prolonged cough). A community-base study in Vietnam reported that prevalence of prolonged cough is not significantly different between men and women (1.3% and 1.5% respectively) (Thorson A, 2000).

A hospital-based study to interview 1,027 smear-positive pulmonary TB patients (diagnosed using direct sputum microscopy examination) in Vietnam reported that prevalence of cough and sputum expectoration among female TB patients was
significantly less common than among male patients (Long, 2000). Further, the absence of these symptoms was significantly associated with increased doctor delays among both men and women. Another study in New York city also reported that absence of cough (OR(adj.) 2.9, 95% CI 1.2-6.8) is significantly associated with longer health care system delays (Sherman et al.). These key symptoms suggestive of TB reflect lesions in lungs, and become more prominent with progressive pulmonary involvement (Banner, 1979). A study from Japan suggests that the stage and the extent of lung lesions are less advanced among female than among male TB patients (Matsushita et al., 1996). There are biological and immunological evidence suggesting that men may have more infectious TB (smear-positive pulmonary TB) than women (Bothamley, 1998).

In addition, in many societies, coughing and spitting up sputum are not socially accepted, especially among women. This cultural belief prevents women from deeply coughing and spitting up a good sputum sample, therefore, the probability of finding AFB in the sputum produced by women is likely to be lower than by men.

**Health system related factors**

Globally, direct sputum smear examination by microscopy is the key diagnostic method for smear-positive pulmonary TB. It is strongly recommended by WHO and IUATLD to apply to all people with a cough for more than 3 weeks. However, a population-based study reported that among people with a cough for more than 3 weeks presenting to hospitals, much fewer women than men were requested to have a sputum test for AFB (14% and 36% respectively) (Thorson., 2000). A study in New York city also reported that not having a chest radiograph at the first medical visit (OR(adj.) 2.4, 95% CI 1.0-5.4) is significantly associated with longer health care system delays (Sherman LF 1999). A study in Ghana also shows that doctor’s delay was longer among women than among men, and increased doctor’s delay was significantly correlated with rates of failure to perform sputum microscopy (Lawn et al., 1998). A study in Ho Chi Minh City (Vietnam) concluded that delay to diagnosis of TB in this city was due more to inability among health care providers to detect TB than to under-utilisation of health care services. Private physicians used X-rays, sputum smears, and referrals significantly less often than public health care providers (Lönnroth et al., 1999). A study in Malaysia on 97 patients with newly diagnosed
pulmonary TB reported that the majority of the patients consulted private general practitioners but the diagnosis of TB was rarely suspected; chest X-ray and sputum examinations were under-utilised (Liam and Tang, 1997). A study in Japan, that found doctor's delay was longer for women than for men, and this difference was mainly attributed by insufficient medical check-up, e.g., delay in chest X-ray examination or ordering no sputum examination in spite of recognition of abnormal shadows on chest X-ray (Sasaki et al., 1996; 2000). A study carried out by Steen et al. in Botswana reported that delayed sputum examination despite prolonged productive cough was common (Steen et al., 1998).

Interaction between patient/family and the health care system
A study in Colombia reported that the cultural-based explanation patients give to the symptoms, the stigma attached to the disease, and the poor quality of health care services (communication skills, organisational structure, attitudes, and knowledge of the TB control strategy of health care workers) are strong barriers to early diagnosis (Jaramillo, 1998).

A qualitative study of Johansson et al (2000) reported a limited interaction between doctor and patient, where the patient had not really understood the doctor’s message. It demonstrates not only lack of trust in the doctor, lack of transparency and poor communication between the doctor, patient and family but also the power relationships between the head of family and his wife. Contacts between doctor, patient and family appeared to be sparse. Staff at the TB facilities had rarely met with the patients’ families during the time patients were admitted to hospital.

Another aspect of a limited interaction was that mentioned previously, in which several male doctors in Vietnam described a non-functioning communication between male doctors and female patients. Male doctor’s difficulty in dealing with female patients reflects well Parsons’ theory on ‘asymmetry’ between doctor and patient (Johansson, 2000). As noted earlier, this is a serious observation of significance for TB diagnosis and treatment, since it may contribute to unnecessary delay in the diagnosis of women.
Socio-economic and cultural factors

Women often have poorer geographic access to health care than men

Geographic access can be evaluated in two ways: distance and travel time. A study in Vietnam reported that although there is no significant difference between men and women in term of geographic distance from home to the hospital and TB facility, the travel time to these facilities is significantly longer for women to come there due to their poorer access to fast means of transport, e.g., motorcycle [Long et al., 2000].

In Vietnam, women are mainly restricted to household chores, child rearing and expenses for daily meals (Anh, 1991). They are perceived to be very busy the whole day long with "‘un-named’" housework, taking care of children, chickens, and hens, taking care of the house, as well as farming. Therefore, it could be difficult for women to find time for hospital examination (Johansson et al., 1999). Women were perceived to have less social contacts than men (Long et al., 1999). This may also prevent women from seeking health care from qualified health care providers, e.g., hospitals, which are quite far away from home.

A study in Tanzania reported that patient’s delay is significantly longer in rural areas, for patients with lower level of education, for those who first visited a traditional healer, and for patients who had no information on TB prior to diagnosis. Due to socio-economic barriers, women are likely to experience these factors more commonly than men (Wandwalo, 2000)

Women often have less economic access to health care than men

In many low-income countries, women often have a lower social position and poorer access to economic resources, education, and information than men. These gender differences influence both health risks among women and care-seeking behaviour (Paolisso and Leslie, 1995). In the family, men often have the last word in making decisions about production, business, and the allocation of household resources (Que et al., 1999). The power sphere of women is restricted to household chores, child rearing and expenses for daily meals. The household income and large expenditures are often controlled by husbands (Anh, 1991). The husband is seen as the head of the family. Female subordination in the family is closely linked to their subordinate economic roles (Liljestrom, 1991). Studies in rural communes reveal that male labour
usually has higher prestige and is more economically productive, as indicated by the fact that almost all-male labour produces income. Women work more, but only a part of their work brings income.

Although economic resources are available in the household, important expenditures are often dictated by male heads of household. In Vietnam, large expenditure (e.g., buying luxury items, building or repairing the house, wedding or other important events) and health care expenditures were significantly more commonly decided by the husband (46.7% and 40.6% respectively) than by the wife (14.3% and 19.1% respectively), p=0.000 [Long, 2000]. A household survey in rural Appalachian reported that women perceived financial barriers to health care significantly more than men, even when living in the same household (Beck et al., 1996). An in-depth interview study with new pulmonary TB patients in Zambia reported that economic burden of TB creates barriers to prompt diagnosis of the disease, and important economic barriers include transportation expenditure, cost of “special food”, and lost income (Needham et al., 1998).

Due to lack of proper economic and geographic access to hospital and TB care services, women often seek health care from providers close to their homes, e.g., self-medication, health care providers at grass-root level and private practitioners. This results in longer diagnostic delays and more health care visits among women than among men before the disease is diagnosed.

Social isolation, stigma and misperception of TB

As described earlier, fear of social isolation was a strong element in denial of disease in women in Vietnam, resulting in a variety of reactions and delay. Some women related in FGDs how they had denied suspicion of TB and avoided diagnosis and thus confirmation of the disease because they had feared that the family and the neighbours would avoid them. Fear of enacted stigma was the main concern of women at suspicion of TB, in health care-seeking and in compliance with treatment. Women even isolated themselves because of felt stigma and for fear of enacted stigma. Men did not demonstrate the same fear of enacted stigma. The main reactions
to both felt and enacted stigma were denial and concealment of the disease leading to self-medication, delay in health care-seeking and interruption of treatment; these latter may in their turn lead to severe forms of TB, development of chronic cases, drug resistance and death.

In the period of HIV/AIDS epidemics, the social isolation and stigma toward TB patients has become more serious, especially among women. In Chiang Rai (Thailand), a qualitative study reported that people had good knowledge of AIDS but they knew little about TB. People defined persons losing weight, having fever and cough as having AIDS, rather than TB. This resulted in delay in seeking care in patients who suspected they had AIDS, and feared AIDS detection. Although less than AIDS, the community stigmatised TB patients because of it being contagious and easily transmitted through exhalations, foods and drinks and closeness to TB patients. Stigmatisation of AIDS and inadequate knowledge of TB can result in delay in seeking TB care and in treatment non-adherence (Ngamvithayapong et al., 2000).

In addition, information suggests that more commonly than men, women did not come back to the health facility on the second day when they were requested to bring the second sputum specimen taken at home. This may be due to several factors including that women are busy with children, housework, and dependent on the husband and in-laws, and lower access to hospital care. These factors need further investigation.

In many low-income countries, women cannot decide themselves to seek health care, but the decision is often made by the husband or senior members of the family. As a result of their subordinate roles in the family, they depend on men or elder women for expenses and mobility in the event of illness and disease. Untimely access to health care is also a result of restrictions on women’s mobility and seclusion of women in the household (Okojie, 1994). Furthermore, due to lack of information, women themselves may not recognise the early symptoms of diseases. All these factors may lead to poorer health status and poorer access to health care services among women, and therefore, women may receive less adequate health care than men (Key, 1987).
Conclusions

The importance of a gender perspective on current policies regarding disease prevention and treatment is slowly being recognised. What has been introduced and presented in this chapter is the growing evidence of the strong influence of gender on the possibilities of getting a successful diagnosis, treatment and cure of tuberculosis. So far this aspect has not been fully acknowledged within programmes targeting fight against TB. Given the available information, policy and programme managers need to identify gender sensitive recommendations to improve the current TB control policies and programme.

Given the relatively recent progress within the research area, there is also still a great need of future research activities. This subject was discussed in detail during a recent workshop on gender and tuberculosis organised at the Nordic School of Public Health. Population based epidemiological studies are needed to find the "true" prevalence and incidence of TB and clinical progression and treatment characteristics of TB among men and women. Further, a limited scientific knowledge exists on the influence of sex on the immunology and genetic aspects specific of TB. This is an area that may be of importance to future development of more effective diagnostic methods of TB as well as for an increased understanding of the sex-specific differences in TB epidemiology and clinical presentations. The qualitative studies here presented have been carried out in Vietnam, and they have to an extent contributed to the existing knowledge in the social beliefs and consequences of TB in this area. However, similar studies need to be conducted in different cultural settings in order to contextualize effectively global TB programme recommendations. Evidence from different cultural settings is also needed regarding health seeking behaviour among TB suspects and the utilisation of private and public health sector among men and women.

There is thus an urgent need of increased awareness regarding the existing knowledge of the impact of gender on TB as well as of further explorations within the research area.
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