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## Gender and tuberculosis control Perspectives on health seeking behaviour among men and women in Vietnam

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### Abstract

This study explores the perspectives of tuberculosis patients on which factors influenced their health seeking behaviour, with special reference to gender differentials in terms of delays in health seeking. In 1996, a multi-disciplinary research team carried out 16 focus group discussions. The study was done in four districts in Vietnam, both in the south and north of the country and in urban and rural areas. Qualitative analysis of data was performed following general principles of modified grounded theory technique. Participants in the focus groups described three main factors as contributing to delay in health seeking. These were fear of social isolation, economic constraints and inadequate staff attitudes and poor quality of health services. A model illustrating different factors influencing health seeking was elaborated and served as a basis for discussion of the findings. The main factor contributing to delay among women was described as fear of social isolation from the family or the community. Stigma was described as closely related to contextual factors such as gender-roles, socio-economic status and level of education and seemed to be mediated via denial and concealment of tuberculosis diagnosis and disease, thus causing delay. The main

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factor contributing to delay among men was described as fear of individual costs of diagnosis and treatment. Staff attitudes and quality of health service facilities were described as not always corresponding to people's expectations of appropriate health services. Women saw themselves and were seen by others as being more sensitive than men to poor service conditions and staff attitudes. A typical feature of the described health seeking behaviour of men was that they neglected symptoms until the disease reached a serious stage, by which time they tended to go directly to public health services without first visiting private health practitioners. Women, on the other hand, were described as having a tendency to seek out private services and practice self-medication before seeking care at public services. In conclusion, there is a need for better understanding of behavioural factors and for developing strategies, that take these into account. Health workers need to better understand gender and social aspects of tuberculosis control, particularly aspects that influence the likelihood for achieving equity in diagnosis and cure. © 2000 Elsevier Science Ireland Ltd. All rights reserved.

*Keywords:* Vietnam; Tuberculosis; Health seeking behaviour; Gender; Stigma; Focus group discussion

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## 1. Introduction

Sex and gender have been acknowledged only recently as factors of importance in understanding patterns of disease as well as being recognised by investigators and policy-makers as providing insight into the control of infectious diseases [1]. While sex refers to the physiological differences between men and women, gender refers to the variety of behaviours, expectations and roles that exist within a social, economical and cultural context.

It has been reported world-wide, that health seeking behaviour in general differs considerably between men and women. Timyan et al. [2] reported that women, because they have little access to information, often are poorly informed about their health and therefore fail to recognise early symptoms. Women tend to wait longer to seek treatment when ill and are less likely than men to consult modern health services [3]. It has also been recognised, that staff at health facilities often treat women as being inferior and that women therefore are hesitant to seek treatment [3]. Finally, when women themselves are patients, their productive and reproductive work is unlikely to be fully replaced by other family or community members [4], presumably leading to reluctance or inability on their part to fully adopt a sick role.

Studies have shown that female cases, e.g. of malaria and leishmaniasis, are subject to under-notification. A study in Thailand [5] showed that six times as many men as women attended malaria clinics, although disease prevalence was the same in both sexes. Similar results were found in Colombia when cases of leishmaniasis [6] were investigated through active case finding. The disease was found to be equally prevalent among men and women although previously it had always been considered twice as common in men. The studies also investigated the reasons behind the findings. Time constraints, the preference for traditional healers and cost and mobility factors were identified as some of the barriers to females seeking health care.

In this study of gender and health seeking, tuberculosis (TB) has been chosen as a tracer disease. Tuberculosis is likely to have particularly adverse consequences for women because of the social stigma associated with the disease. In a previous study in Vietnam, TB patients were found to consider themselves 'dirty' and were also looked upon as 'dirty' [7]. However, little is known about how stigma of TB influences health seeking from a gender perspective.

The term stigma is used to refer to an attribute that is deeply discrediting [8]. One can distinguish between enacted and felt stigma. Enacted stigma refers to episodes of discrimination against people on the grounds of social unacceptability or inferiority; while felt stigma is based on a deep sense of inferiority and refers to an oppressive fear of enacted stigma.

Tuberculosis is a serious public health problem. About eight million new cases of TB are reported in the world annually, one third of the world's population is infected by *Mycobacterium tuberculosis* and three million people every year as a consequence of TB [9]. At present, more HIV-infected individuals die from TB than from any other cause. Furthermore, TB kills more women than all causes of maternal mortality combined [10].

Tuberculosis treatment has been available at a moderate cost since the mid-fifties and the World Bank has identified TB treatment as one of the most cost-effective public health interventions [11]. During the last decade, the long lasting decrease in the incidence of TB has been reversed and the incidence has once again started to raise. Some well-known reasons for this are the HIV/AIDS epidemic and weak TB control programmes with subsequent poor treatment compliance, resulting in the development of drug and multi-drug resistant strains of *Mycobacterium tuberculosis* [12].

The estimated male to female ratio of TB cases reported to public authorities world-wide is two male cases for every female case [13]. Similarly, two thirds of the newly detected cases in Vietnam are men (Annual Report, TB programme, Vietnam, 1995; [14]). The TB case fatality rate, however, is higher among women and this is also the case world-wide [15,16,13]. It is not known whether there is a genuine difference in incidence related to sex or a difference in notification rates caused by gender-related differences in health seeking behaviour or access to health services, or a combination of both [17].

Based on the patho-physiology of the disease, support from the literature and clinical experience, we developed a conceptual framework for a research project on TB, health seeking behaviour and gender. We assumed that gender roles and socio-economic status are the main contextual factors which influence the disease process, either directly or indirectly, via the stigma attached to the disease (Fig. 1).

The aim of this study was to explore and describe perceptions of factors influencing health-seeking behaviour in Vietnam, with specific reference to gender differentials in delay in health seeking. Health seeking behaviour should here be seen as representing the range of activities that individuals undertake to promote and/or restore health [18]. The following questions were addressed: How does context (gender roles, socio-economic status, education) influence health seeking behaviour? How is stigma expressed? How do stigma and delay in health seeking

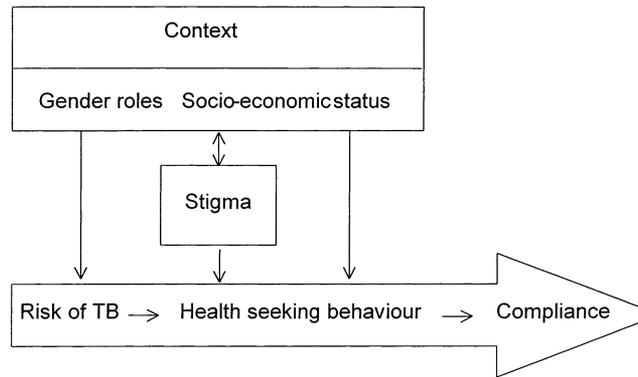


Fig. 1. Conceptual framework: direct and indirect influences of contextual factors (here assumed to be gender roles and socio-economic status) on the process of getting TB to the state of being cured from TB.

relate to each other? How do staff attitudes and quality of health facilities influence health-seeking behaviour?

## 2. Subjects and methods

### 2.1. Vietnamese context

In 1986, the Government of Vietnam launched an initiative for reform, known as Doi Moi. The whole country is moving from its centrally planned economy to one of market orientation. A number of measures have been designed to liberalise new resources for the health sector. These include introduction of user fees, the legalisation of private practice, sale of drugs in the open market and a health insurance system with primary focus on state employees [19].

The reform has brought about not only economic growth, but also increased income disparities and problems with access and utilisation of health services. Currently, the public sector faces challenges in the forms of a dramatic decrease in the utilisation of public health facilities and a shift towards self-medication and private practice. The quality of public facilities has deteriorated following the agricultural reform with a decollectivisation process, where funds supplied by collective farming incomes disappeared. A majority of the rural population presently obtains their health services on a fee for services basis. The structural change is likely to have contributed to poor conditions of services, especially at commune level and has at the same time negatively influenced the possibility for poor people to seek health care.

An impact of the reform on vertical programmes, such as the TB control programme, can now be seen in increased difficulties for patients to pay for services. Although TB drugs are free of charge, considerable amounts might have to

be paid for a visit at a public health facility, not to mention the costs for 1–2 months of hospitalisation, which is the recommended treatment for TB patients.

Vietnam was one of the few low-income countries that introduced TB control activities early on (in 1957). The current TB programme (after reforms in 1986 and 1996) is based on the strategy recommended by WHO, directly observed therapy (DOT), i.e. supervised swallowing of drugs at the health centre or at home. It has been suggested, that the requirement of supervision in the DOT strategy is insensitive to large groups of the population, especially women in low-income countries. A recent randomized controlled trial from South Africa compared compliance with treatment between hospital-based DOT patients and self-supervised TB treatment patients [20]. The trial found that the two methods were equally successful in men (61% with DOT and 64% with self-supervision) while in women DOT was less successful (38% with DOT and 55% with self-supervision).

Despite the early introduction of TB control, the TB situation in Vietnam is comparable to that in other developing countries, with TB being one of the leading causes of death among adults (Annual Report, TB program, Vietnam, 1993; [21]. The notification rate of TB was 74.8/100 000 for 1995 [22]. In 1996 the National TB programme found a multi-drug resistant TB rate of 2.3% and a resistant rate to any TB drug of 35.5%. Luckily, TB/HIV is still rare.

Anti tuberculosis drugs are free of charge for patients treated ‘within’ the national program. However, drugs are also available at most pharmacies and can be bought without prescriptions [23,7].

Each Vietnamese district hospital has five to ten beds for TB patients. Smear-positive pulmonary cases are diagnosed in the districts, using direct microscopy, while smear-negative pulmonary and extra-pulmonary cases are diagnosed at the provincial centres. The majority of TB patients are diagnosed, managed and controlled by the district TB units. A decentralisation process of TB activities has been initiated by the programme, with the aim to move TB control activities from the districts to the communes.

In Vietnam, the family is the unit for reproduction and production [24–26]. Men and women are mutually dependent on each other’s work and all members of the rural family are key participants in different stages of farming and gardening activities. Both men and women perform income-generating labour. However, men are seen socially as the ‘pillar of the family’ and play, together with their parents, a major role in decision making and issues taking place in the ‘public world’.

## *2.2. Study design and methodology*

The study was performed during 1996 and took place in four purposively selected districts in the provinces of Hanoi, Quang Ninh, Ho Chi Minh City and Quang Nam-Da Nang, both in the south and north of the country and in urban and rural areas. The aim of the study was to explore perceptions, beliefs, knowledge and attitudes related to TB among Vietnamese men and women with and without TB.

As the aim of the study was to highlight issues of importance for health seeking behaviour in male and female TB patients, a qualitative design, within the natural-

istic paradigm [27] including focus group discussions (FGD) for data collection and modified grounded theory technique for analysis of data [28] was chosen. It was important to use a qualitative methodology in order to find a large variety of perceptions and experiences of health seeking behaviour among male and female TB patients, much of which was previously not well known. The emergent design made it possible to use findings from one FGD to re-formulate themes for the next one. The reason for choosing FGDs as the data collection technique was to utilise properties of group dynamics in order to study the breadth of experience of respondents, thereby gaining maximum variation of answers with adequate depth. The interaction between participants in the groups can provide valuable, sometimes unexpected, information and understanding [29]. Focus group discussions indicate the range of a community's beliefs, ideas, opinions and attitudes and are valuable for gaining base-line information. The method has limitations in explaining complex beliefs of individuals (for which in-depth interviews are needed) [29]. The risk that FGDs paint a picture of what is socially acceptable instead of what is really occurring or believed to be occurring can be limited with careful participant selection and good moderating skills.

Four FGDs were conducted in each of the four districts. Groups consisted of men with TB, men without TB, women with TB and women without TB. Participants with own TB experience were purposively selected from the district TB register by the researchers and the local TB team. Inclusion criteria were: 15–60 years of age, proved sputum positive and detected during the last 12 months. Men and women without TB were recruited among neighbours (with a similar socio-economic status) to the selected TB patients. The groups consisted of eight to ten participants and were relatively homogeneous with respect to socio-economic status, but not with respect to age. Participants were unknown to each other. Potential participants were verbally introduced (following a written information) to the study in their homes by the research team a few days before the FGD was planned to take place. The participants were assured of confidentiality and the possibility to withdraw at any time. There was no problem with participants not wanting to participate in the FGDs; on the contrary, also non invited TB patients turned up and expressed an interest in taking part in the discussions. However, these latter patients were sent home again.

The research team was multi-disciplinary and consisted of one Swedish nurse tutor (EJ) and one Vietnamese epidemiologist/medical doctor (NHL), supervised by two Swedish senior researchers (VKD and AW). The team was assisted by one Vietnamese sociologist, medical doctors and translators, thus representing both insider and outsider perspectives.

Each FGD was conducted by a moderator (a Vietnamese sociologist in two FGDs and a Vietnamese epidemiologist, NHL, in 14 FGDs). A pre-tested line of themes was used as a basis for the discussions in the FGDs. As new data emerged during the discussions, some themes were dropped and some others introduced instead. Sessions lasted for 1–2 h. The FGDs were tape-recorded, transcribed in Vietnamese and then translated into English. Two of the FGDs were translated into English by two independent translators in order to check the accuracy of the

translation. There was a high degree of concordance between the translations. Techniques used in the study to assure truth value were prolonged engagement (long period in the field), triangulation (use of multiple researchers) and peer debriefing (sharing results with colleagues).

Data were analysed inductively, i.e. raw data were transformed into categories which were not predetermined following general principles of modified grounded theory technique [28]. During analysis, open codes were applied to segments of the text by two independent researchers (EJ and NHL) and results were then discussed with the whole research team. Constant comparison among open codes was made between men and women, participants from rural and urban areas, participants with own TB experience and without any own TB experience and participants from the south and north of the country. Data were reorganised accordingly and categories were created from the open codes. In qualitative analysis, the aim is to explain patterns and linkages between different descriptive units. Theories emerge from the data, rather than being predetermined before the data collection from already existing theories [27].

Ethical approval was obtained from Karolinska Institutet, Sweden, Ministry of Health, Vietnam and the National Institute of Tuberculosis and Respiratory Diseases, Vietnam.

### 3. Results

Themes were introduced and questions were asked by the moderator of the FGDs. This was done in two ways; either by asking for participants' thoughts about the general opinion in the community or by asking for participants' own experiences of a certain issue. Own experiences were sometimes asked for as a complement to and an illustration to what was considered the general opinion in the community. The results mainly describe participants' own views and experiences of TB and TB control, but also sometimes what participants considered to be the general opinion in the community. Where participants describe general opinion more than their own experiences, this is clarified in the text.

Major categories identified during the coding process are presented below. Most differences were seen between men and women, some between participants from urban and rural settings and a few between participants with TB and participants without TB experience. In as much as no substantial differences were found between participants from the north and the south, this distinction is not highlighted in Section 3.

#### 3.1. *Previous and current perceptions of TB*

Focus group participants perceived that knowledge about TB and TB control varied considerably between old and young, between educated and less educated (the latter meaning none or very few years in school) and between people in urban settings and those living in remote areas. The discussion covered the issue of TB

and was seen to be regarded (by others) as a dangerous disease, which affects people of all ages and in particular poor people. The traditional Vietnamese view of TB as ‘an incurable disease’ [7] was described and respondents believed it was still the prevalent perception, predominantly among the elderly and less educated people. The elderly in the countryside were described as ‘backward’ and unwilling to go for treatment. All these perceptions were more based on the perceived general opinion in the community than on own experience. The following metaphor, expressed by one of the participants, illustrates the view on TB as a deadly disease.

“There are caves in the lungs. Blood came out as water comes out from a basket with a lot of holes in it. Limbs can be bandaged, but how can lungs be bandaged?” (Woman, non TB, rural, north)

Some participants demonstrated good knowledge of TB and TB control, in raising the issue of the importance of coming early for diagnosis and treatment in order to stand a better chance of curing the disease.

Different types and causes of TB were discussed in all the FGDs. It was obvious that a few men and women still adhered to the traditional way of identifying four different types of TB [30]: ‘Lao tam’, believed to be caused by worries and too much thinking and mainly affecting women; ‘Lao luc’ believed to be caused by hard work without enough food and rest and mainly affecting men; ‘Lao truyen’ believed to be a hereditary disease ‘in the blood’ handed down in the family from generation to generation; and ‘Lao phoi’ believed to be a contagious type of TB. However, some participants objected to these descriptions of the disease and its causes and appeared to be well aware of modern science and explanations of the disease, including the risk for drug resistance.

An interesting phenomenon encountered in the groups, was the difference in attitudes to TB among participants with TB experiences of their own and participants without such experiences. People with their own TB experiences tended to have acquired a more traditional way of viewing TB, while people without any TB experiences of their own advocated a more modern way of viewing TB.

FGD participants in all groups raised the issue of fear of social consequences of the disease, i.e. isolation of the individual within the family and/or isolation of the family in the community. Both male and female participants expressed this fear. It was, however, concluded in the groups that fear of social isolation was most common among women, elderly and farmers with low education. The next quote is an illustration of the fear of being infected by one’s spouse, which leads to the spouses distancing themselves from each other.

“If the husband gets TB, the wife becomes frightened and cannot feel normal in the relationship. We call it ‘the kiss of death’.” (Man, TB, rural, north)

### 3.2. Hidden costs

Even though TB drugs are free of charge for patients treated within the TB programme, all other costs for diagnosis and treatment fall upon the individual him- or herself. Participants in all the FGDs brought up this type of individual expenses as a main obstacle to seeking medical care in order to confirm suspected diagnosis or to receive proper treatment. Some participants expressed how expenses had exceeded their available resources. The imbalance between the availability of resources and the accessibility to health services for people in remote mountainous areas as compared with people in the rest of the country was discussed. A man from the rural north describes difficulties encountered by people living in remote areas in these words.

“Many people come from remote areas. They have neither resources nor available facilities for treatment. They die as ‘victims of injustice’.” (Man, TB, rural, north)

In conformance with existing national guidelines, it is recommended that TB patients should be admitted to hospital during the first 2 months of treatment. Some participants emphasised that hospitalisation had contributed to increased expenses and loss of income for them as individuals. The only alternative available for them as poor people had been to practice self-medication or to borrow money, the latter resulting in debts that for some had taken years to pay back. How difficult it might be to initiate and comply with treatment and still earn a living is described by a woman below.

“At night he has to drive a 3-wheel cyclo. In daytime, he has to carry bricks for construction workers. He works very hard all day. He comes home at 10 pm and the next day he has to start work at 5 am. He works like that continuously. He coughed and when he took an X-ray, he was told, that he had TB. What could he do?” (Woman, non TB, urban, south)

### 3.3. Gender roles in the family

Men and women in the groups described the characteristics of the two different gender roles in similar terms. Men were characterised as hard-working, yet having leisure time, as being independent, as being the ‘pillar of the family’, as having an extensive social network and enjoying the right to ‘go out’, as having less responsibility towards their wives than wives towards them, as being more respected than women and as receiving more attention than women.

Women were characterised as being dependent on husbands and their families, as being patient, as being afraid of divorce and death, as thinking a lot and always worrying, as being responsible for how to spend the money of the family, as

carrying out lighter work but still being hard-working and always occupied with work, having no leisure time, as always being at home taking care of the children, as having few friends and as being ‘less important’ than their husbands, for example, meaning that they would not be taken care of, or be taken to the hospital if they fell ill in the same way as the husband would.

The ‘pillar of the family’ was considered so important that he (in a few cases, she) was constantly prioritized at the expense of other family members. In case of TB, the family would make sure that the ‘pillar of the family’ was diagnosed and treated before other family members. A wife was expected to care for her husband, while the husband was not subjected to the same expectations. The following metaphor illustrates the importance and role of the ‘pillar of the family’.

“Individuals, who are pillars of the family should be taken care of by the family. If the head of the train is strong, it can pull the whole train, if the head is weak, the whole family will come into a difficult situation.” (Man, TB, urban, south)

The influence of parents-in-law on younger women in the family was described as strong. Parents-in-law were sometimes said to have a harmful influence, as they were not always well educated and therefore, still adhered to old beliefs and traditions (e.g. that TB was congenital and incurable). A woman describes the dependency of a woman living in the husband’s family as follows.

“Women, who live with the husband’s family and do not earn any money, are very dependent on other family members, who influence their possibility to make decisions.” (Woman, non TB, urban, north)

The general picture of men, described in the FGDs, was quite clear and unequivocal, while the picture of women was more complicated. The majority of the participants described the role of women as related above, but another, slightly different picture of women also became evident. It described a woman with a slightly more independent role in the family. The different role of this woman seemed to depend on whether she earned money herself and if she and her husband lived separated from her parents-in-law or not.

The perceptions of gender roles were largely based on a mixture of own experiences and the general opinion of the participants and perceived opinion of other people in the community.

### *3.4. Public and private health services*

Attitudes, competence and working conditions of health staff were in varying degrees discussed in all the FGs and a variety of views and opinions, sometimes contradictory, emerged.

A general critique of staff and health facilities was conveyed by the participants, based on their own experiences. Some participants described staff as being cold, angry and not very involved in their work, while others described them as being

supportive and good. The importance of a good patient–staff interaction for success in the treatment of patients is described below.

“Although it was poor, the doctor’s attitude was dedicated and warm. It made the patients believe in the treatment.” (Man, TB, urban, north)

A certain trust in hospitals, medical doctors and other staff was demonstrated. In case of a serious disease like TB, it was agreed among participants that a hospital with medical doctors was to prefer to a private practice. Commune Health Stations (CHS) were heavily questioned and criticised in the groups for low competence of staff, who also were accused of ‘pretending to know everything’. Young doctors were criticised and some participants expressed scepticism as to their competence and experience — ‘a good and experienced doctor should be old’. How one female patient experienced treatment at the commune health station is described below.

“Sick people, who come to the CHS are received coldly. The staff let them wait for a long time, get angry with them and are not involved. People are not satisfied with the services of the CHSs’.” (Woman, TB, rural, north)

Criticism was also levelled against the physical condition of TB health facilities, especially in rural settings. They were described as poor, making people feel uncomfortable and ill at ease. Waiting time was experienced as long. Participants believed that doctors were probably influenced by the poor conditions of the facilities and by their low salaries. Participants suggested, that improving the conditions for doctors would probably lead to doctors becoming more dedicated and patients more compliant. The following quote illustrates how one man experienced the TB health facility during his first visit.

“The first time I came here, I could not believe that this was where TB was treated. The conditions were very poor, but the doctors were very gentle and kind hearted.” (Man, TB, urban, north)

People also experienced the public health services as being bureaucratic and formal. Private doctors were described as kind and involved, as having no waiting time, but also as charging more for treatment than doctors in public services. A majority believed that private doctors provided a poor alternative in the case of TB, which was believed to require more facilities than private doctors could offer, for example X-ray examination of the lungs. One person also mentioned that private doctors sometimes were afraid of TB patients as the doctor could get a bad reputation if the patient did not recover promptly.

Private practitioners, a more diffuse group-by some participants called ‘quacks’, were criticised and said to endanger patients’ lives due to lack of competence. However, some participants expressed a preference for them as they operate close to where sick persons live.

Attitudes of staff in TB health service facilities seemed to be of significant importance. Some FGD participants told how explanations, that had been given to them by the doctors concerning diagnosis, treatment and prognosis, had been well received and had had great influence on their health behaviour and wellbeing. Several participants expressed a dislike for being looked down upon or treated as if they 'did not understand anything'. The importance of attitudes of doctors and other staff was emphasised repeatedly.

“Though it is poor here, the doctor’s attitude is dedicated and warm. This makes the patients believe in the treatment. At first I was very worried and frightened, but the doctor here is good, she encouraged me to follow the treatment and to get the disease completely cured.” (Man, TB, urban, north)

### *3.5. Denial of TB especially among women*

Denial of the disease was described by both men and women. By denial in this context we understand the tendency to ‘lie’ to oneself about the suspicion of having TB.

A pattern, that came out strongly, was the phenomenon of denial of the first symptoms of TB. The first symptoms were in many cases interpreted as a common cold or flu. The fear of getting TB is illustrated in the next quotation.

“Nobody believes that they can have TB. Even when they go to hospital for examination and the doctor tells them that they have TB, they still do not believe it. They think that their cough is simply a symptom of flu or common cold.” (Woman, TB, rural, north)

Men described denial as a reaction, more or less related to poverty and fear of losing one’s source of income and thereby the possibility of supporting the family. Women described denial as a quite common but complicated phenomenon. Women related denial to fear of social isolation and fear of seeking help at public health facilities. The weak position of women in the family was believed to contribute to denial. A tendency to practice self-medication was also said to play a role in the denial process and appeared to be more common among women than among men. However, women also took the initiative to treat other members of the family. A man from the south speculates below, that women practice self-medication because they are afraid to lose their health.

“In my opinion women buy drugs first. The reason is that women often worry more about their health than men.” (Man, non TB, urban, south)

In conclusion, fear of stigma was described as a strong element in denial of the disease in women, resulting in odd reactions and delay. Some women concluded,

that they had denied suspicion of TB and avoided diagnosis and thus confirmation of the disease, because they had feared that the family and neighbours would avoid them. It was obvious that fear of social isolation among women strongly contributed to the denial of obvious TB symptoms. Denial because of fear of social isolation is illustrated in the next citation.

“I think that women always worry and are afraid of TB. So if people suspect that a woman has TB, she will not dare to go for examination, but when we encourage her or force her, she will go, but unwillingly. Women feel upset and they are afraid that their family and neighbours will keep away from them.” (Man, non TB, urban, south)

### *3.6. Concealment of TB diagnosis*

Hiding disease is another phenomenon causing delay in health seeking, not as common as denial, but of great importance for the health seeking process. By hiding we understand concealing the fact that one has TB. Hiding the disease, knowing about it, but without initiating treatment, is a serious matter where the TB afflicted individual remains a serious source of infection and where others may not be aware of the risks.

Reacting to a TB diagnosis by concealing it, appeared to be closely linked to the stigmatising effect of the disease and the fear of consequences of stigma. Some participants described that they were afraid of disclosing the truth out of a sense of shame at being diagnosed with TB and possibly being the only one in the family ever to have suffered from the disease. The fear of losing friends and neighbours and not being able to socialise with others were also mentioned as strong contributing factors to reactions of concealment of the disease. The extent to which people succeed in concealing the TB diagnosis is illustrated below.

“Right in my hamlet, I had not seen anybody saying that they had TB. So when I went to the TB clinic, I thought that I was the only one with TB, but it was so crowded — there was not even a place to stand.” (Woman, TB, urban, south)

Women expressed a fear of losing the opportunity for unmarried sons and daughters to get married and of themselves losing their husbands. Participants generally thought that women were most likely to hide their diagnosis. An additional contributing factor to hiding the diagnosis, expressed by the women, was the fear of seeking help at hospitals and other health facilities, the reason being that the hospital environment was seen as strange and frightening. Another consequence of stigma raised in the groups was the fear of not being able to start or to continue with business, especially if it was related to sales or dealing with food. As the following quote illustrates, some people seek private treatment because of a wish to remain anonymous.

“Some patients get treated by private doctors, because they want to hide the disease. In hospital they might be recognised. Especially, rich people want to maintain their social relations and business relation.” (Man, TB, urban, south)

Hiding might have serious consequences as illustrated below.

“She had gone for examination and the doctor told her, that she had TB. She was very afraid. She did not tell anyone in the family about it. Then, when her disease got very serious, everybody knew that she was ill and I took her to hospital. When we got to hospital, the doctor said that her TB was too serious. Five days later, she died.” (Woman, non TB, rural, south)

### *3.7. Typical health seeking behaviour in men and women*

In summary, participants described and summarized the typical health seeking behaviour of men and women as follows. The typical health-seeking pattern of men was said to mainly consist of neglecting symptoms until the disease was in a late stage. They further tended to go straight to public health services without an initial visit to a private practitioner or an attempt to practice self-medication. Women, on the other hand, were described as having a different sequence of health seeking behaviour, characterised by a first visit to a private practitioner and/or self-medication before seeking care at public health services.

## **4. Discussion**

This study provides popular views on gender differences in health seeking behaviour and main contributing factors to delays in health seeking. In summary, three main contributing factors to delays in health seeking were identified. First of all, stigmatising effects of TB seemed to be mediated through denial and concealment of TB diagnosis and disease and thereby causing delay in health seeking—a pattern seen especially in women. Secondly, respondents expressed a fear of high individual expenses for diagnosis and treatment leading to delay or total avoidance of public health facilities, particularly among men. Thirdly, health facilities, especially at commune level but also at TB facilities, did not correspond to people’s expectations of appropriate public health services in terms of material resources and human competence. Women were believed to be more sensitive to deficiencies in conditions of facilities and attitudes of staff than men. Staff attitudes seemed to be of great importance for lay trust and confidence in staff and treatment. Private health services and self-medication were sometimes preferred to public services, which could sometimes cause delays in the health seeking process, including diagnosis and initiating treatment.

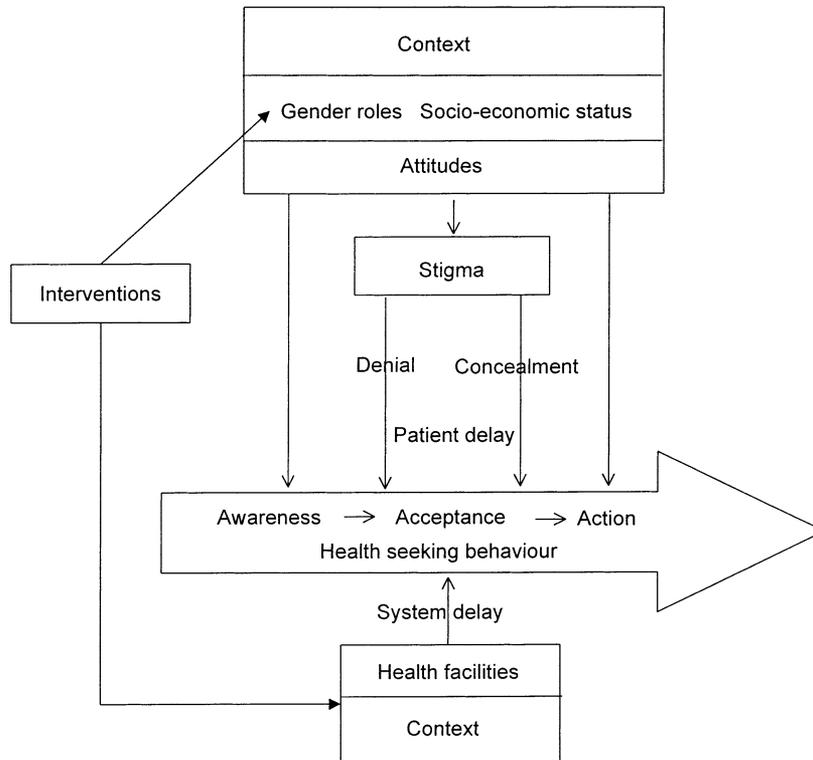


Fig. 2. Direct contextual influence on health seeking behaviour and indirect influence on health seeking behaviour mediated via stigma, denial and concealment of disease.

Methodological strengths and weaknesses should be taken into account when considering implications of the results. A pre-requisite for assuring the quality of data was the collaboration between Vietnamese and Swedish researchers. The benefits of the interaction between participants would not have been achieved had the moderator not been Vietnamese. A methodological difficulty encountered was the hierarchy that developed between the participants according to age. The oldest participant would start to talk and the others would follow suit according to their respective ages. This rather hierarchical order had an inhibiting influence on the exchange of views and the flow of discussion in the focus groups. It would probably have been better to have a composition of participants of the same age in the FGs, thus allowing for a more lively discussion, not inhibited by age differences. Previous experience of moderating FGDs and a good cultural understanding was essential in coping with the situation. In spite of these weaknesses, we consider the findings of the study valid and credible.

A model for how social context of TB relates to stigma, mediated via denial and concealment of disease and actual health seeking behaviour was developed (Fig. 2). The model forms the basis for further discussion.

Social context of TB here encompasses factors such as knowledge and image of TB, socio-economic status, education, family structure (composition of the family living in the same household) and gender roles. Norms and attitudes may vary between different groups in the society. Elderly people with a low level of education, e.g. consider TB to be dangerous and possibly an incurable disease, whereas young, well-educated people consider TB to be a curable disease. Socio-economic status, family structure and gender are other factors influencing attitudes and behaviour. Vietnam is a society in rapid transition. I must therefore be assumed, that a variety of norms and attitudes prevail in different social classes, in different age groups and in groups living in different parts of the country, sometimes contradicting each other.

Health-seeking behaviour was strongly influenced by family structure and gender roles. Concerns of men and women were different because of their different roles in family and society. Being dependent on husband and in-laws, women feared rejection by husbands, other family members and society, while men worried more about loss of income and other financial difficulties. Lifooghe et al. [31] similarly reported from Pakistan how TB in one of the spouses could lead to divorce or separation. The risk of divorce was perceived to be greater for women than for men.

Stigma seemed to be a summary effect of contextual factors mediated via denial and concealment of disease; both phenomena more common among women than men and leading to delay (as illustrated in Fig. 2). Delay took different forms: as denial and/or hiding of disease, here called patient delay; and as system delay, caused by health services and other system-related factors. Similar findings of how social stigma of TB contributed to lengthy delays in seeking professional care and concealment of disease have been described by Rubel and Carro [32]. They reported from Mexico how social stigma affected patients' familial relations. Fifteen percent of the patients expected to be rejected by their families, when they returned home from hospital. In an unpublished study among immigrants in California, Rubel reported that many patients had not mentioned to those with whom they lived the nature of the disease and expressed fear that the spouse would discover the disease, refuse to eat or sleep with them and sever the relationship.

Quality of health service facilities, as well as competence and attitudes of staff is assumed to be part of the context of TB patients in the model (Fig. 2). Expressed deficiencies in public health services need to be seen in the light of the liberalisation of the economy in Vietnam (Doi Moi), which has brought about not only economic growth, but also increased income disparities and problems with access to health services for the households [19].

Women's higher sensitivity to negative attitudes and behaviour of staff and other deficiencies in the health facilities have also been reported by other authors. Vlassoff [3] has described how women often are treated in an inferior way by the health system and therefore hesitate to seek care. Interaction between

staff and patients appears to be of great importance for the trust and confidence in health institutions and treatment. Consequences of poor attitudes and behaviour of staff has also been described by Smith [33] from his experience in Nepal, where health workers frequently responded aggressively to people who finally presented for treatment in terminal stages of TB. He concluded, that such attitudes may make the patients feel threatened, uncomfortable, unwelcome and unwilling to return. It is important to take consequences of poor care into consideration. Donabedian [34] has for example stated that poor care that can harm patients as well as being wasteful and that waste in any form depletes resources that could be used to treat more patients better.

All the factors mentioned, which influence health seeking behaviour, can be classified as either individually-related factors or system-related factors, where delay is caused either by the patient him/herself or the system. Both patient and system-related factors can be influenced by interventions of various kinds such as health education, reduction of total costs of treatment for individual TB patients, decentralisation of TB services and improvement of salaries and working conditions for staff, all in order to influence/change context and thereby improve health seeking behaviour.

Our findings have implications for TB control in Vietnam. The trend of an increased prevalence of TB leading to increased incidence of infection needs to be broken. Gender-sensitive strategies need to be developed in order to solve problems involved in delay in the process of health seeking. Comprehensive services are of importance at all levels of the health system, in order to make them more accessible and affordable, for both men and women and where poor as well as people living in remote areas can be reached.

Health workers need to gain an improved understanding of sociological and gender aspects of TB control, particularly those that influence the likelihood of diagnosis and cure. In teaching health workers about TB control, we tend to concentrate on technical aspects, while there is a great need for better understanding of behavioural factors and for developing strategies, that take these into account. There is also a need to organise training in such a way that staff become aware of their own limitations, reflect upon them and take responsibility for their own processes of change. The whole setting such as working environment, equipment and facilities, communication, management and leadership must be taken into account at the same time if quality improvements are to be sustainable. There is a need to involve staff in a continuous process of assessing and improving the quality of care.

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