

# THE FEELINGS AND EXPERIENCES OF PATIENTS WITH TUBERCULOSIS IN THE SEKONDI-TAKORADI METROPOLITAN DISTRICT: IMPLICATIONS FOR TB CONTROL EFFORTS

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## SUMMARY

**Objectives:** To explore the feelings and experiences of TB patients, and to highlight how TB stigma may affect case finding and compliance with treatment.

**Design:** Qualitative research approach using focus groups and individual interviews

**Setting:** Sekondi-Takoradi Metropolitan district, Ghana

**Participants:** Purposeful selection of TB patients receiving TB at four government hospitals in the district

**Intervention:** None

**Results:** Because of TB stigma, majority of the patients failed to recognise their symptoms as due to TB, and attributed it to malaria and ordinary cough. They reported to the hospital only after prolonged period of self-medication in the community, with some indicating multiple visits before a diagnosis was made. When diagnosed, some were worried and cried, questioned how they got the disease, contemplated committing suicide, and others doubted it was TB. Most of them hid the diagnosis from others, and were isolated within the family and community.

**Conclusions:** Most TB patients failed to recognize their symptoms as due to TB, because of the stigma attached to the disease in society. The way people treat those with TB, especially close contacts is also a source of worry to the patients. This may lead to delay in reporting to the hospital and consequently increase mortality from the disease. It may also make it difficult for the patients to comply with the long duration of TB treatment.

**Key words:** tuberculosis; TB stigma; TB patients; Ghana

## INTRODUCTION

Ghana launched a National Tuberculosis Control Programme (NTP) in 1994, and relies on passive case finding approach in making a diagnosis of tuberculosis (TB). This meant that individuals recognising their symptoms as due to TB and self-report to the hospital

for diagnosis and treatment. More than a decade after successful implementation of strategies aimed at encouraging people suffering from symptoms suggestive of TB to seek early treatment, case finding has been very low.<sup>1-3</sup> One factor identified as contributing to the low TB case detection and compliance with treatment is the stigma attached to the disease in most societies.<sup>2-6</sup>

Stigma is socially constructed and evolves from at least two fundamental components: (1) the recognition of difference based on some distinguishing characteristics or mark; and (2) consequent devaluation of the person.<sup>7-10</sup> Indeed, when an individual is noted as possessing an attribute that is different from that which society expects him/her to possess, the outcome is 'a spoiled social identity.'<sup>9</sup>

Such a mark of deviance then initiates an attributional process through which people interpret other aspects of the person, and respond to the stigmatized individuals on the basis of their stigma at the expense of their individuality.<sup>8</sup> Ultimately, stigma creates social boundaries between those regarded as normal by a society and those that are stigmatised.<sup>11</sup>

It is therefore important to understand the social milieu in which patients seek medical services and the negative effects these may have on the patients as well as the TB control programme. The aim of this paper is therefore to report the feelings and experiences of TB patients in an urban district in Ghana, and to highlight how TB stigma may affect the motivation to search for diagnosis and efforts to comply with treatment.

Such an understanding would aid in the development of strategies and interventions to counteract the effects of stigma on TB patients and help to achieve the Millennium Development Goals (MDGs) and the Stop TB partnership targets of halving TB mortality and prevalence by 2015.<sup>12</sup>

## SUBJECTS AND METHODS

This paper draws on six focus groups and 34 individual interviews conducted with TB patients in the Sekondi-Takoradi Metropolitan district in the Western Region of Ghana. The study had ethical approval from the Ghana Health Service Ethical Review Committee.

The participants were purposely selected using the TB registers in four (out of seven) government institutions providing TB services in the district. The four hospitals were selected because they offer both in- and out-patients services for TB patients. Selected patients who were still receiving treatment at the start of the study had the rationale of the study explained to them at the clinic, while those who had completed or defaulted from treatment were traced to the addresses indicated in the TB register to invite them to take part in the study.

Data was collected in two phases: the focus groups were conducted first and later the individual interviews. Patients who participated in the focus groups were excluded from the individual interviews. Both the focus groups and individual interviews were conducted in the local language (Twi) at venues within the hospitals. The individual interviews were conducted face-to-face with the patients at TB clinics.

The focus group sessions were moderated by the author, who introduced the topics, while research assistants, trained to help with data collection, recorded the discussions on audio tapes and took notes. Each focus group session lasted 1-2 hours and comprised 8 to 12 participants, aged between 14 to 69 years. Details of the focus group participants are shown in Table 1.

**Table 1** Background information of TB patients

Group	No. per group	Age range	Occupation (number)
Female group	8	23-55	Trader 2; Hairdresser 1; Seamstress 1; Fishmonger 1; Unemployed 2; Student 1
Male group 1	9	26-58	Mason 1; Electrician 1; Fisherman 1; Shoemaker 1; Carpenter 1; Painter 1; Labourer 1; Trader 1; Unemployed 1
Male group 2	12	14-46	Salesman 1; Electrician 2; Farmer 1; Labourer 2; Student 1; Plumber 1; Quarry Worker 1; Unemployed 3
Mixed group 1 (10 Males & 2 Females)	12	21-69	Security 1; Retired 2; Quarry Worker 1; Bookbinder 1; Driver 1; Unemployed 5; Sailor 1
Mixed group 2 (8 Males & 4 Females)	12	17-52	Truck pusher 1; Trader 1; Student 1; Hairdresser 1; Seaman 1; Tailor 1; Unemployed 6
Mixed group 3 (10 Males & 2 Females)	12	27-56	Quarry 1; Farmer 2; Painter 2; Driver 1; Seaman 2; Electrician 1; Seamstress 1; Salesman 1; Fishmonger 1

The topics discussed were based on the literature, personal knowledge and experience of working in the TB control programme. The topics were the same for both the focus groups and individual interviews, and explored the health seeking behaviour, feelings and experiences with TB, and how they cope with the disease.

Immediately after each data collection activity, the research assistants used the recorded audio tapes and field notes to literally translate and transcribe verbatim all the interviews into English.

The author then used the audio tapes and field notes to cross-check each transcript, ensuring that they were correctly translated to preserve the meaning of the participants' words and statements, and provided feedback to the research assistants. The data analysis was facilitated by NVivo software (QSR International Pty Ltd. Australia, Version 2.0).

The analytic approach used was influenced by Grounded Theory techniques and procedures.<sup>13</sup> The transcripts were read through, line-by-line, to identify key concepts, called 'nodes' in

NVivo, and these nodes were used to develop a coding framework for coding the data. The coding process involved reading the transcripts, linking and connecting texts to the nodes they represent. As data analysis progressed, identified concepts were organised into discrete categories and subcategories.<sup>13</sup> This was done through manipulation and organisation of free nodes into tree nodes, resulting in the creation of a hierarchy of nodes containing categories and sub-categories.

## RESULTS

### *Onset of symptoms*

At the initial stages of the disease, the majority of the patients did not recognise their signs and symptoms as due to TB.

According to most of them, when the symptoms started, they thought it was due to malaria or ordinary cough. They went to the nearest drug stores to buy cough remedies and other drugs. Moreover, because of the non-specific nature of the symptoms, and the belief in the use of traditional medicines, some patients mentioned visiting spiritual homes, known locally as 'nankaba garden', and churches, where they were given herbal remedies, 'holy waters' and oils to use.

In certain circumstances, they consulted health professionals residing in the community for assistance. It was only when these 'searches' did not result in improvement in the symptoms that they decided to go to the hospital:

*...I started feeling feverish and thought it was malaria so I sent for drugs from the drug store. ...Later I started to cough...Then a time came that any time I ate, I vomited everything...Within days I grew very lean, so I decided to stop taking the drugs and go to the hospital... (Male patient, focus group)*

#### *Visiting the hospital*

For the majority of the patients, the decision to go to the hospital was influenced by family members and close friends, most of whom had had TB in the past, and recognised the signs and symptoms as due to TB. Others indicated listening to a discussion of TB on the local radio station, and sometimes on television, during which they recognised that their symptoms were likely to be due to TB, so they took the decision to go to the hospital. When they finally decided to go to the hospital, most of them indicated multiple visits, sometimes moving from one hospital to another and were treated for many conditions and diseases before the diagnosis of TB was finally made:

*...the sickness started about four months ago...I came here (the health facility where the interview was conducted) and was given treatment but I was still coughing so I went to SDA (Seventh Day Adventists) clinic. I later went to Effia-Nkwanta hospital, where I did sputum test...and was referred to CDU (Communicable Diseases Unit) and they in turn referred me here... (Female patient, individual interview)*

Some of the patients did not tell the attending physician that they have been coughing for long periods, and had taken various medications without improvement before reporting to the hospital. They rather mentioned various non-specific symptoms, concealing the more specific ones, such as, prolonged cough and sometimes haemoptysis, which could be helpful in making the diagnosis of TB:

*... I thought it was malaria so when I went to the hospital I told the doctor that I am having headache and feeling feverish. He treated me for a long time before I told him that I am also coughing. He then asked me to do sputum test and chest X-ray which showed that I had TB... (Male patient, focus group)*

Most patients indicated that they found the attitudes and behaviours of health professionals towards them demeaning. They described such attitudes as affecting their confidence and the way they related to others in the community. Others pointed out that it discouraged them from reporting to the hospital:

*...when I went to Accra, I met a lady doctor; the woman has no patience at all! When you cough, she will shout at you saying "gentleman, go there, go there". The way she behaves means that when you have this disease, you should not come near her; she hates you. When it happened like that, I decided to stop going there and came here instead...there are some people who wouldn't like to be treated like that, so they would not go to the hospital just because of the way she will treat them... (Male patient, focus group)*

#### *Reactions to the diagnosis of TB*

Most of the patients indicated expressing various forms of emotion when informed they have TB. Some of them said that they were shocked, scared, confused, and cried throughout the night because they thought they would die. Others said they were worried, and wanted to commit suicide:

*...when the doctor completed the investigations and said it was TB, I went home and informed my wife; she cried a lot. So when the doctor said that, I thought of poisoning myself. Anytime I am walking to the hospital and see a train passing, I hear something telling me to throw myself under the train and be killed; just because of this disease that I have... (Male patient, individual interview)*

Some of the patients also mentioned that when they were told the diagnosis, their concern was how to raise money for treatment. Those who indicated that they knew others, who had lost their job because of TB, said their concern was the likelihood of losing their jobs. The majority of the patients, however, questioned how they got the disease:

*...people said the disease comes about as a result of smoking cigarette and drinking alcohol; I stopped these things a long time ago. I do not eat from the street; I give money for my meal to be prepared at home, so I do not know how I got the disease. I thought maybe it is through too much thinking... (Male patient, focus group)*

The pronouncement of the diagnosis aroused spiritual awareness, especially belief in the healing power of God in some of the patients. However, other patients indicated that they doubted the diagnosis, and made the attempt to cross-check the correctness of the diagnosis:

*...I was shocked and doubted the results at that time, so I tried to find out if it was not a mistake from the laboratory; I was very confused and we talked for about 15 minutes and he (the doctor) said there were a lot of people waiting outside... (Female patient, individual interview)*

Notwithstanding the fact that at the time of the interviews, all the patients were receiving treatment for TB, some of them said they did not know what they were being treated for. They indicated that the doctor(s) conveyed the diagnosis to close relatives or friends so they were not aware of what the diagnosis was. Others also denied that they had TB and insisted they were receiving treatment for a chest infection but not TB:

*...as I was saying, I was not told that it was TB. They said I had infection in my chest which has to be treated for two months; so that was what I told my people when I got home and that is what I tell those who ask me... (Male patient, individual interview)*

### **Living with TB: an isolating disease**

#### *Isolation within the family*

Those patients who managed to get to the hospital and are put on treatment had to endure a lot of emotional problems and difficulties because of the stigma attached to the disease in society. The majority of patients mentioned various forms of negative attitudes and behaviours of close and household contacts. Such attitudes usually began immediately the diagnosis became known to others. Some said they were divorced and their children taken away by their partners, whilst others said they were not allowed to send any child in the household on an errand:

*...there was a boy in my house that I used to send on errands; he watches television in my room, drinks my water and does everything at my place. His mother called him and told him that he should stop coming to my place and that he should not to go when I send him because I am coughing... (Male patient, individual interview)*

Most of the patients revealed that close family members usually avoided sharing household items with them. They indicated that they had to eat alone, using separate plates and bowls. Some also pointed out that they were not permitted to give their left-over food to anybody, especially children, since such an act would be interpreted as intention to infect others. In extreme cases, items used by the patients were separated from

the households', resulting in the isolation of the patient within the family:

*...when I had the disease, I went to Kumasi to inform my mother but she wasn't in the house when I got there, so I went to sleep at my brother's place. The next day, when I got up and was going to take my bath, he gave me a separate sponge and towel and had removed that of his children from the bathroom... (Female patient, individual interview)*

Some of the patients did mention that their close contacts and friends were very supportive. However, the trigger for such supportive attitude was the improvement in symptoms of the disease, particularly, weight gain that accompanied TB treatment:

*...I was staying with my friend in a room we rented together and he ran away from me. All my friends shunned my company because of the disease; I lost a lot of weight. It was when I started treatment and began to gain some weight that they started coming back... (Male patient, focus group)*

#### **Isolation within the community**

Negative attitudes toward those with TB at the societal level were also reported. The patients indicated that it was uncommon to have others sit near them or even shake their hands at public gatherings, such as, at funerals and in church. When they pass by any member of the community, they turn to look at them and, sometimes laugh. They pointed out that when interacting with members of the community, they either move away to stand at a distance or turn their heads in the opposite direction, probably to avoid being infected:

*...I remember when I was diagnosed, I mentioned it to my church elders and they also informed the church members. From that day, I noticed that anytime I go to church and get closer to any of the church members, they would cover their mouth and nose, so I decided to stay away... (Male patient, focus group)*

#### **Personal isolation and self-stigmatisation**

Most of the patients mentioned that the negative attitudes of others affected the way they interacted with both family and community members. Patients living with relatives said they ensured that they had very limited interaction with the family members. They had to isolate themselves, separate their eating bowls and cups from the households', sleep outside, or stay somewhere (after the daily medication) till evening before going home. Socially, some of them had to limit their interaction with friends and other relatives and lived secluded lives:

*...as I said, I had no friends; I always stayed in my room as an 'American' (living on his own and avoiding interaction with other). I live in such a way that I do*

*not disturb others and others too will not disturb me... (Male patient, individual interview)*

Because of the negative societal attitudes, most of the patients indicated keeping the diagnosis secret. When it became necessary to inform others, they did so to very close contacts and family members so as to escape being shunned by others. Some also mentioned cautioning family members not to tell others about the diagnosis:

*...we gossip a lot in Ghana; anyone who gets to know that you have this disease will not even greet you. So it is not good to tell others that you are suffering from this disease; no. You also need to warn your wife that if others get to know that you have this disease, all of you will be despised, so she should not let anybody know of it. Because when you take your bucket to the tap to fetch water, if you are not careful, they will throw it away... (Male patient, focus group)*

The disease also affected the way the patients related with others, especially during interactions with members of the community. When it became unavoidable for them to interact with others, most of the patients said they took measures to avoid infecting them:

*...I ensure that I will not infect others by sitting in the direction of the wind or cover my mouth with a handkerchief when talking or coughing; I also have a container for my sputum... (Female patient, focus group)*

#### *Economic burden*

Some of the effects of TB described by the patients were related to financial difficulties they faced. Female TB patients in particular indicated that they had to stop selling, especially food items, when they developed the disease. They pointed out that although they did so to enable them to concentrate on treatment, if they had decided to continue selling and taking TB treatment at the same time, when the community members get to know they have TB, no one would come to buy from them:

*...I was selling with my aunt in the market when I developed the disease. Few days after I started the treatment, she told me that if others got to know that I go to CDU (Communicable Diseases Unit) everyday, they would not buy her food again. So she asked me to stop coming to help with the selling... (Female patient, individual interview)*

Some said that they lost job opportunities because they were weak, whilst those working had their jobs terminated or were asked to minimise the hours they work. The others pointed out that because of the long duration of treatment, they had to stop working, and in

the end, had lost all their trading capital and had to sell their personal belongings to raise money for the treatment:

*...I was a trader and was travelling around the country selling but because of the sickness, my business has collapsed. I also had a sound system I used to entertain myself with in the market but I had to sell it because of the sickness (female patient, focus group).*

## DISCUSSION

This paper had demonstrated the all-encompassing effect of TB on the lives of patients in this Ghanaian society. As pointed out by the patients, the diagnosis and subsequent initiation of treatment was delayed because most of them attributed their symptoms to other diseases, and spent extended period in the community on self-medications. The misdiagnosis reported at some of the hospitals also contributed to the delayed initiation of treatment.

However, the evidence here suggest that the likely cause of the failure of the patients to attribute their symptoms to TB may be because of the stigma attached to the disease in society. The core feature of stigma is the possession of an attribute that conveys a devalued social identity in a particular context.<sup>7-10 14</sup> The attributes that are stigmatised are often well known and shared in a culture.<sup>7-10,14,15</sup> Consequently, when members of a society become aware that existing stereotypes about certain attributes can be applied to them, such a consciousness is often threatening.<sup>16 17</sup>

For example, in an Ecuadorian community, when patients with symptoms suggestive of TB were asked to undergo laboratory investigation for TB, just the thought of undergoing such a test was sufficient to evoke feelings of depression, loneliness and stigmatisation among them.<sup>18</sup> It is therefore possible that when the patients developed symptoms suggestive of TB, this was disturbing enough to warrant concealment or denial. Indeed, it has been documented that because of the stigma attached to TB, patients often refuse to acknowledge the signs and symptoms of the disease, and explain it as due to non-stigmatising conditions, such as, common cold or malaria, just to reduce the contempt of others.<sup>19-27</sup>

Similarly, the evidence presented here has demonstrated that most of the patients attributed their symptoms to other diseases, and this made them spend extended periods in the community self-medicating. It was only when such searches did not yield any result that they reported to the hospital. This may explain the four months delay in diagnosing TB,<sup>28</sup> and the very low case detection rate of 38% in Ghana.<sup>3</sup>

Furthermore, persons with stigma learn and incorporate the stand-point of non-stigmatised individuals in society and accept the general belief of being stigmatised persons.<sup>9</sup> As had been demonstrated here, the patients are aware of the shame associated with having TB, as evident in the self-stigmatising attitudes exhibited by most of them. Indeed, fear of stigma was evident from the various forms of emotion expressed by the patients when they were told the diagnosis for the first time. Some found the diagnosis difficult to accept or rejected it, whilst others asked that the diagnosis be kept secret or hid it from others. To the extent that some of them indicated they had wanted to commit suicide when they knew they had TB pointed to their awareness about the stigma attached to the disease in society. This demonstrated their understanding of the commonly held view of the lay society about TB, and clearly constituted a major source of anguish to them.

The findings have implications for the TB control programme. For an infectious disease such as TB, prompt diagnosis and initiation of treatment is the best way to minimise the spread of the disease,<sup>2</sup> and because the TB patients are the source of infection, particularly the smear positive ones, if they fail to seek treatment, they will continue to spread the disease in the community.

As has been documented in other studies,<sup>18 20 27 29-37</sup> TB patients in this Ghanaian society demonstrated the awareness of the shame associated with having TB. Consequently, most of them isolated themselves and avoided interaction with others.

Some of them used different names when they came to the hospital or did not want anyone to see them coming into contact with the TB clinic.<sup>38</sup> Others described living secluded lives just to avoid being stigmatised. Some of the patients also pointed out that they had to rely on social support or borrow money as means of coping with the disease. However, for fear of infection, people did not get closer to offer any support.

In most African society, the availability of social support conveys social identity and feeling of belongingness. As such, its absence may lead to variety of stressors which may have negative consequences for the psychological health of the TB patients. This may lead to default from TB treatment as reported in other studies.<sup>25 38-40</sup>

Additionally, mortality from TB is a key performance indicator for the health service, and is also likely to be a significant factor affecting the credibility of the TB control programme in the community.

Since most of the patients reported to the hospital very late, usually in a very bad state, the late initiation of treatment is less likely to improve the prognosis of the disease. Moreover, community interviews conducted in the Sekondi-Takoradi Metropolitan district also found that members of the community knew people, usually family members and close contacts, who had had TB in the past, and were reported to have died.<sup>41</sup>

Such terrible community experience with the disease, over time, can heighten the fear of the disease, since the disease may be viewed as a death sentence,<sup>32 42 43</sup> and therefore be singled out for stigmatisation by the society. Efforts at improving the prognosis of TB treatment should therefore be instituted.

In conclusion, this paper had shown that most of the TB patients failed to recognize the symptoms as due to TB, because of the stigma attached to the disease in society. It has also highlighted the fact that the way people treat those with TB, especially close contacts can be a source of worry to the patients, and may lead them to default from treatment. It is therefore important to work at improving early recognition of symptoms by patients and prompt diagnosis by health professionals, so as to initiate early treatment and improve the prognosis of the disease.

The TB control program should also tailor the health education messages on TB to the community's understanding of the disease, since this has the potential of improving collaboration between the community and healthcare system. Meanwhile, community discussions on TB should be encouraged since such open debate about the disease will encourage those suffering from symptoms suggestive of TB to recognize it and report to the hospital. It may also lead to reduction in the stigma attached to TB in the community, since TB patients may not be seen as deviating from any social norms that may single them out for stigmatization.

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## REFERENCES

1. WHO. *Global Tuberculosis Control. Report 2005*. Geneva: World Health Organization, 2005.
2. WHO. *Treatment of tuberculosis. Guidelines for National Programmes*. 3rd ed. Geneva: World Health Organization, 2003.
3. NTP-Ghana. *Annual Report: National Tuberculosis Control Programme*. Accra: Ghana Health Service, 2004.
4. Weiss MG, Ramakrishna J. *Stigma interventions and research for international health*. <http://www.stigmaconference.nih.gov/FinalWeissPaper.htm> 2001.
5. Weiss M, Ramakrishna J, Somma D. Health-related stigma: Rethinking concepts and interventions. *Psychology, Health & Medicine*. 2006; 11(3):277-87.
6. Lawn SD. Tuberculosis in Ghana: social stigma and compliance with treatment. *International Journal of Tuberculosis and Lung Disease*. 2000;4(12):1190-91.
7. Dovidio JF, Major B, Crocker J. Stigma: Introduction and Overview. In: Heartherton FT, Kleck RE, Hebl MR, Hull JG, editors. *The social psychology of stigma*. New York: The Guilford press, 2000.
8. Jones EE, Farina A, Hastorf AH, Markus H, Miller DT, Scott RA. *Social stigma: The psychology of marked relationships*. New York: Freeman, 1984.
9. Goffman E. *Stigma: Notes on the management of spoiled identity*. London Penguin, 1963.
10. Crocker J, Major B, Steel C. Social stigma. In: Gilbert DT, Fiske ST, Lindsay G, editors. *Handbook of Social Psychology*. 4th ed. Boston: McGraw-Hill, 1998:504-53.
11. Alonzo AA, Reynolds NR. Stigma, HIV and AIDS: An Exploration and Elaboration of a Stigma Trajectory. *Social Science & Medicine*. 1995;41(3):303-15.
12. WHO. *Global tuberculosis control: surveillance, planning, financing: WHO report 2008*. Geneva: World Health Organization, 2008.
13. Strauss A, Corbin J. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. 2nd ed. Thousand Oaks, CA: SAGE Publications, Inc, 1998.
14. Link BG, Phelan JC. Conceptualizing stigma. *Annual Review of Sociology* 2001;27:363-85.
15. Major B, O'Brien LT. The Social Psychology of Stigma. *Annual Review of Sociology*. 2005;56:393-421.
16. Stangor C, Crandall CS. Threat and the social construction of Stigma. In: Heartherton FT, Kleck RE, Hebl MR, Hull JG, editors. *The Social Psychology of Stigma*. New York: The Guildford Press, 2000.
17. Steele CM, Aronson J. Stereotype threat and the intellectual test performance of African Americans. *Journal of Personality and Social Psychology*. 1995;69(5):797-811.
18. Armijos RX, Weigel MM, Qinchu M, Ulloa B. The meaning and consequences of tuberculosis for an at-risk urban group in Ecuador. *Revista Panamericana de Salud Publica/Pan American Journal of Public Health*. 2008;23:188-97.
19. Cambanis A, Yassin MA, Ramsay A, Bertel Squire S, Arbide I, Cuevas LE. Rural poverty and delayed presentation to tuberculosis services in Ethiopia. *Tropical Medicine & International Health*. 2005;10(4):330-35.
20. Liefoghe R, Baliddawa JB, Kipruto EM, Vermeire C, De Munynck AO. From their own perspective. A Kenyan community's perception of tuberculosis. *Tropical Medicine and International Health*. 1997; 2:809-21.
21. Long NH, Johansson E, Diwan VK, Winkvist A. Different tuberculosis in men and women: beliefs from focus groups in Vietnam. *Social Science & Medicine*. 1999;49 (6):815-22.
22. Eastwood SV, Hill PC. A gender-focused qualitative study of barriers to accessing tuberculosis treatment in the Gambia, West Africa. *International Journal of Tuberculosis and Lung Disease*. 2004;8(1):70-75.
23. Dick J, Schoeman H, Mohammed A, Lombard C. Tuberculosis in the community: Evaluation of a volunteer health worker programme to enhance adherence to anti-tuberculosis treatment. *Tubercle and Lung Disease*. 1996;77:274-79.
24. Liam CK, Lim KH, Wong CMM, Tang BG. Attitudes and knowledge of newly diagnosed tuberculosis patients regarding the disease, and factors affecting treatment compliance. *International Journal of Tuberculosis and Lung Disease*. 1999;3(4):300-09.
25. Johansson E, Long NH, Diwan VK, Winkvist A. Attitudes to compliance with tuberculosis treatment among women and men in Vietnam. *International Journal of Tuberculosis and Lung Disease*. 1999;3(10):862-68.
26. Weiss MG, Ramakrishna J. Stigma interventions and research for international health. *Stigma and Global Health: Developing a Research Agenda. An International Conference*: <http://www.stigmaconference.nih.gov/FinalWeissPaper.htm> 2001.

27. Macq J, Solis A, Martinez G, Martinez P, Dujardin B. An exploration of the social stigma of tuberculosis in five "municipios" of Nicaragua to reflect on local interventions. *Health Policy*. 2005;74:205-17.
28. Lawn SD, Afful B, Acheampong JW. Pulmonary tuberculosis: diagnostic delay in Ghanaian adults. *International Journal of Tuberculosis and Lung Disease*. 1998;2:635-40.
29. Khan A, Walley J, Newell J, Imdad N. Tuberculosis in Pakistan: socio-cultural constraints and opportunities in treatment. *Social Science & Medicine*. 2000;50(2):247-54.
30. Baral S, Karki D, Newell J. Causes of stigma and discrimination associated with tuberculosis in Nepal: a qualitative study. *BMC Public Health*. 2007;7(1):211.
31. Bennstam AL, Strandmark M, Diwan VK. Perception of Tuberculosis in the Democratic Republic of Congo: Wali Ya Nkumu in the Mai Ndombe District. *Qualitative Health Research*. 2004;14(3):299-312.
32. Long NH, Johansson E, Diwan VK, Winkvist A. Fear and social isolation as consequences of tuberculosis in VietNam: a gender analysis. *Health Policy*. 2001;58(1):69-81.
33. Atre SR, Kudale AM, Morankar SN, Rangan SG, Weiss MG. Cultural concepts of tuberculosis and gender among the general population without tuberculosis in rural Maharashtra, India. *Trop Med & International Health*. 2004;9(11):1228-38.
34. Hansel NN, Wu AW, Chang B, Diette GB. Quality of life in tuberculosis: Patient and provider perspectives. *Quality of Life Research*. 2004;12:639-52.
35. Rajeswari R, Muniyandi A, Balasubramanian R, Narayanan PR. Perceptions of tuberculosis patients about their physical, mental and social well-being: a field report from south India. *Social Science & Medicine*. 2005;60(8):1845-53.
36. Zhang T, Liu X, Bromley H, Tang S. Perceptions of tuberculosis and health seeking behaviour in rural Inner Mongolia, China. *Health Policy*. 2007;81(2-3):155-65.
37. Somma D, Thomas BE, Karim F, Kemp J, Arias N, Auer C, et al. Gender and socio-cultural determinants of TB-related stigma in Bangladesh, India, Malawi and Colombia. *International Journal of Tuberculosis and Lung Disease*. 2008;12(7):856-66.
38. Dodor EA, Afenyadu GY. Factors associated with tuberculosis treatment default and completion at the Effia-Nkwanta Regional Hospital in Ghana. *Transactions of the Royal Society of Tropical Medicine and Hygiene*. 2005;99:827-32.
39. Meulemans H, Mortelmans D, Liefoghe R, Mertens P, Zaidi SA, Solangi MF, et al. The limits to patient compliance with directly observed therapy for tuberculosis: a socio-medical study in Pakistan. *International Journal of Health Planning and Management*. 2002;17(3):249-67.
40. Ngamvithayapong J, Winkvist A, Diwan V. High AIDS awareness may cause tuberculosis patient delay: results from an HIV epidemic area, Thailand. *AIDS*. 2000;14(10):1413-19.
41. Dodor EA, Kelly S. 'We are afraid of them': Attitudes and behaviours of community members towards tuberculosis in Ghana and implications for TB control efforts. *Psychology, Health & Medicine*. 2009;14(2):170 - 79.
42. Liefoghe R, Baliddawa JB, Kipruto EM, Vermeire C, DeMunynck AO. From their own perspective. A Kenyan community's perception of tuberculosis. *Tropical Medicine & International Health*. 1997;2(8):809-21.
43. Dodor EA, Neal K, Kelly S. An exploration of the causes of tuberculosis stigma in an urban district in Ghana. *International Journal of Tuberculosis and Lung Disease*. 2008;12:1048-54. ✱