

PUBLIC LECTURE

UNIVERSITY OF SYDNEY, 5<sup>TH</sup> OF AUGUST 2008

Qualitative study of barriers to and enabling factors for tuberculosis treatment adherence in Timor Leste.

Dr Nelson Martins, MD, MHM, PHD,

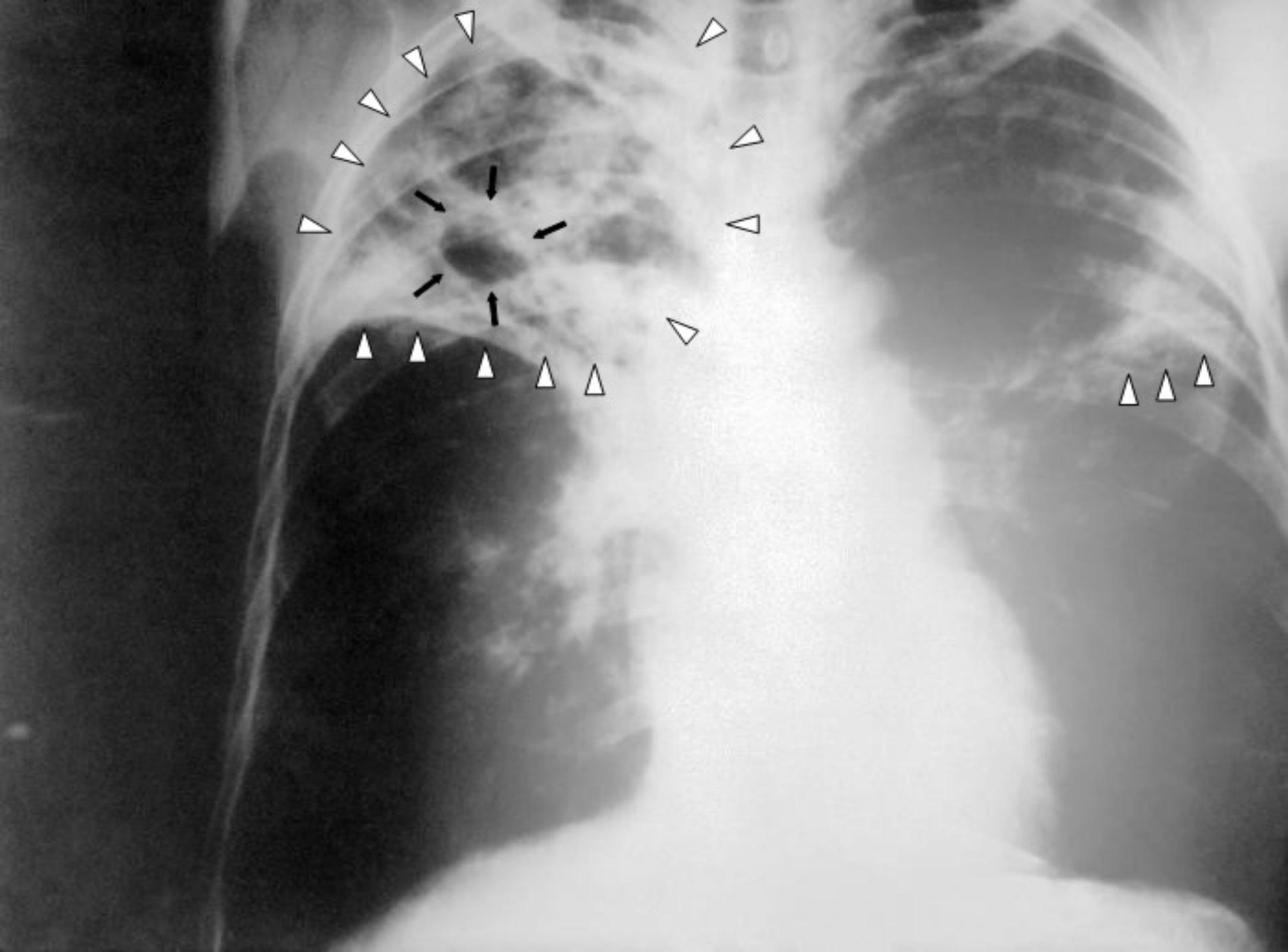
# History, Definition and Etiology

- TB-ancient disease : 4000 BC
- Up to an early 19th Century : Hippocrates : Clinical entity
- 1882 : infectious disease : Robert Koch identified *Mycobacterium TB (MTB)*.
- Definition : an infectious disease caused by mycobacterium complex, but mostly by MTB

# Pathogenesis & Classification

Davies PDO clinical TB,1998

- TB infection occurs : when a person inhale a small, moist, expectorated droplets containing MTB from smear positive TB patients who coughs laughs or speaks
- 95% infected person resolve spontaneously, 5 % become sick .
- Pulmonary and Extra-pulmonary TB



# Diagnosis

Davies PDO clinical TB,1998

- Clinical symptoms :  
Cough more than 3 weeks,  
tiredness, malaise, anorexia, pyrexia,  
amenorrhoea in females, weight loss, and night  
sweats.
- Found MTB in the sputum and other body fluid and  
tissues

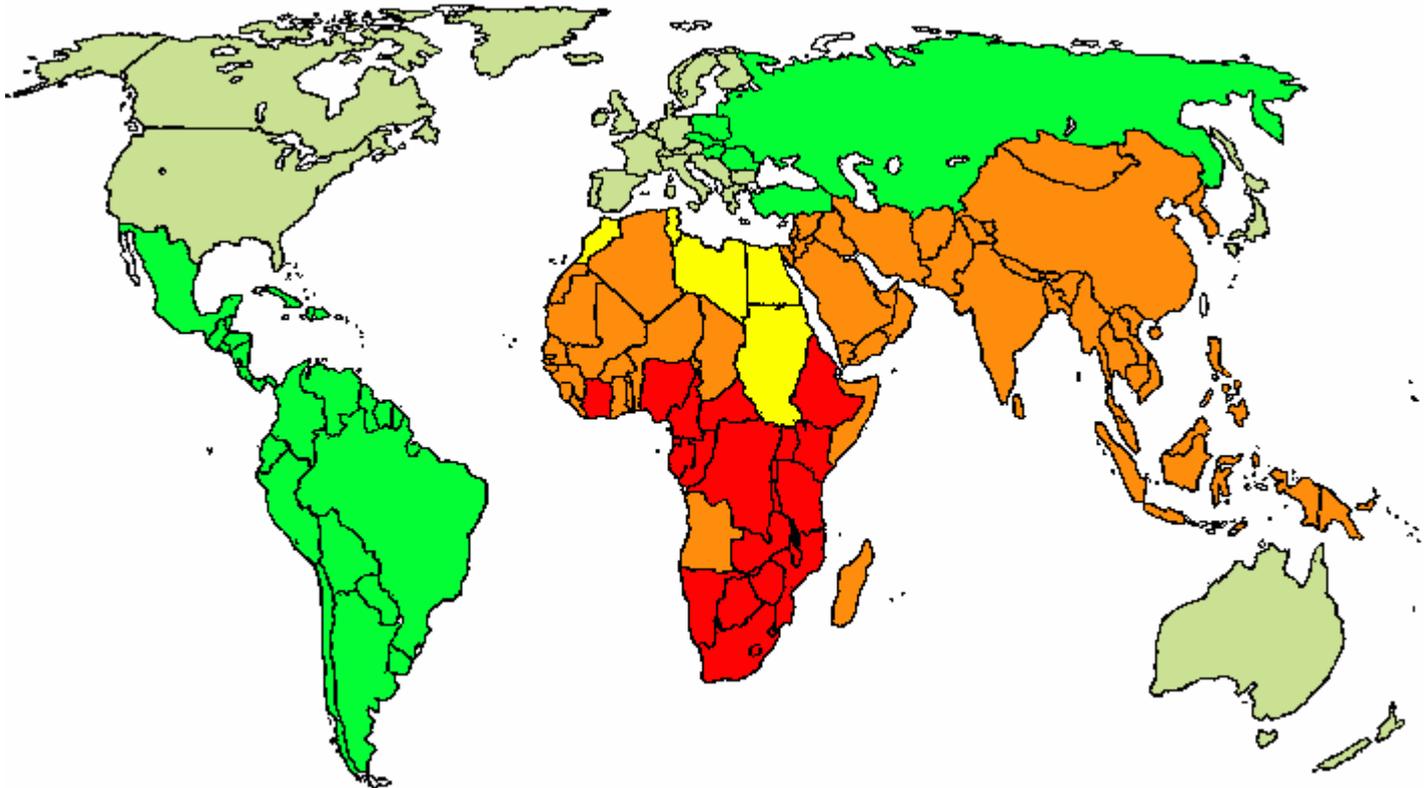
5 4 2001



# Epidemiology of TB

World TB incidence.

Cases per 100,000; Red = >300, orange = 200-300; yellow = 100-200; green 50-100 and grey <50. Data from WHO, 2006.



**WORLD**

Political Map



North Pacific Ocean

Arctic Ocean

CANADA

UNITED STATES OF AMERICA

North Atlantic Ocean

South Pacific Ocean

South Atlantic Ocean

North Pacific Ocean

Indian Ocean

Southern Ocean

INTERNATIONAL DATE LINE

Copyright © 2008 www.mapsofworld.com

0 600 1800 3000 4200 Kms.

ANTARCTICA

# WHO- Directly Observed Treatment Short Course (DOTS) Strategy

Maheer D., Mikulevica M , WHO,1999

- ❑ In 1993, WHO declare TB as global emergency
- ❑ In 1993, WHO introduce DOTS strategy with its 5 Components to fight TB in developing countries
  1. Political Commitment
  2. Case detection using sputum microscopy
  3. Standardized short course chemotherapy with Directly Observed Treatment (DOT)
  4. A regular drug supply
  5. Standardized Recording and Reporting System

## TB PROBLEM IN TIMOR LESTE

- In 2004 , TB case notification rate for all cases was 403/100 000 and
- For new smear positive cases it was 108/ 100,000
- It was the highest TB notification rate reported in the **South East Asia and Western Pacific Region**

Martins et al, 2004, IJTLD

# WHAT & WHY WE DO THIS STUDY

- A recent review of qualitative research pertaining to TB treatment adherence found that patients' decisions to cease TB treatment were influenced by a complex interaction of structural, personal and health service factors operating within a societal context.<sup>7</sup>
- It is important for NTPs to perform locally-based studies to investigate possible impediments to treatment completion and to find local solutions to improve DOTS performance.<sup>8</sup>

Two objectives:

1. To identify barriers to TB treatment adherence, and
2. To identify factors that could assist TB patients to complete their treatment.

# WHERE



- Timor Leste is a newly independent country, with a population of a little over one million people, living in 13 districts.<sup>9</sup>
- The majority of the population lives in rural areas as subsistence farmers, 42% of the population lives below the poverty line, with an estimated adult literacy rate of less than 60%.<sup>9</sup>

The two sites to reflect :

- 1) Different levels of accessibility of TB services;
- 2) The highest default rates in the country.

## The demographic, geographic, ethnic and TB health services profile of the study districts.

	Dili	Ermera
Special Features	The , main sea and air ports, centre of government administration and economic activity	Main coffee growing area, limited other economic and government activities
Population*	137,959, high population density	103,169, low population density
Ethnic Background	Multiethnic	Mainly <i>mambae</i> people, with <i>kemak</i> and <i>bunag</i> minority
Location and Topography	Central North coastal area, low land, hot, humid, less rain during the wet season	58 km southwest of Dili, high land, Cold, heavy rains during the wet season
TB notification rate, 2004 (all cases ) <sup>†</sup>	1,353/100,000 population	158/100,000 population
TB health services <sup>†</sup>	4 Diagnostic centres 5 DOT centres	1 diagnostic centre 6 DOT centres
Time to Diagnostic and treatment centre (average)	30-45 minutes walk	120 minutes walk

# HOW

- Routinely collected NTP data was examined to assess case holding rates in every district of Timor Leste.
- Within Ermera District, the villages from which the highest number of defaulters had originated were selected for particular attention.
- In these selected sites, all TB nurses and a snowball selection of the defaulting patients (who ceased treatment for  $\geq 2$  months) and patients who completed treatment during 2003 were invited to participate in this study.
- In addition community members, including members of youth and women's groups, traditional leaders and village heads, were invited to take part in focus group discussions.
- The principal author, NM, two local research assistants. They had the advantage of being both insiders and outsiders. As insiders they were able to communicate fluently with the participants, and understood local social and cultural nuances. The team's outsider status is due to their education and training in medicine and research methods, an educational background which is not shared by the participants in this study.

# How -continue

- The researchers began their fieldwork with participant observation, visiting TB clinics, patients' houses, and traditional sacred places. Fieldwork took place over a three month period, from April to June 2004.
- 28 in-depth interviews (patients, TB nurses) and 7 FGD with community members (12 per group) were conducted. Standardised, open-ended interview schedules were developed.
- Interviews were tape recorded, and hand-written notes were taken, which as soon as possible afterwards, were transcribed in detail by each of the research assistants, and checked by NM. Any inconsistencies identified were addressed by reviewing notes and recordings, and referral to interviewees.
- Triangulation : the standard method of combining multiple observations, theories, methods, and data sources.<sup>10</sup> The data was analysed by NM using content analysis to compare differences between the responses of the two categories of patients (defaulters and completers), TB nurses and community members. Key categories which emerged from the data were counted and recorded.
- The results of the preliminary data analysis were critically assessed by JG (Medical Anthropologist) and PK (Public Health Physician/TB Specialist), and their recommendations informed the revision of the analysis and the final presentation of the findings.
- Ethical clearance was granted by the Human Research Ethics Committee of the Charles Darwin University, Darwin, Australia and by the Minister for Health, Timor Leste. All participants provided written informed consent.

# WHAT DO WE FOUND

- Rapid symptomatic improvement was both a barrier and an enabler to treatment completion, patients either interpreting the improvement as meaning they were cured (and thus defaulted), or knowing they were getting better and wanting to complete the treatment until they *were* cured.
- Various economic, geographic and health system issues also had an important influence on treatment adherence.
- Treatment defaulters and community members possess low levels of knowledge about TB when compared to patients who complete treatment. TB nurses possessed good knowledge about TB and DOTS, and were highly committed to their work.
- Satisfied with the current TB services in their local clinic vs Health worker negative attitudes

# WHAT DO WE FOUND- Continue

## *TB health beliefs*

Some respondents regard “*Mear Ran/haemoptysis*” as an inherited disease which they believe occurs because there was “a killing in their family tree and this is a major reason for stigma surrounding the disease.

*For example, there is a killing inside the family, even though it is in the war such as in 1975, when we killed one of our relatives such as [an] uncle, brother or sister, etc... we will get the blood (mutah ran) one day in our life. This might not directly affect the murderer, but for sure it will happen to one of his/her descendents.*

Community members, Ermera.

# Barriers and Enabling factors to completion of TB treatment

Reasons For*	Dili-Urban	Ermera - Rural	Summary of Main Categories†
Default	<ul style="list-style-type: none"> <li>• Feel Improved</li> <li>• Transport costs</li> <li>• Disease became severe</li> <li>• Busy with school</li> </ul>	<ul style="list-style-type: none"> <li>• Feel Improved</li> <li>• Taking traditional medicine (instead of TB treatment)</li> <li>• Living far from TB treatment centre</li> <li>• Transport costs</li> <li>• Could not walk</li> <li>• Busy with work</li> <li>• No symptomatic improvement</li> </ul>	<ol style="list-style-type: none"> <li>1. Symptomatic improvement</li> <li>2. Economic and geographical barriers</li> <li>3. Worsening of patients' condition</li> <li>4. Interfering with important daily activities</li> </ol>
Complete	<ul style="list-style-type: none"> <li>• Knowledge of the disease and strong willingness to be cured.</li> <li>• Symptomatic improvement</li> <li>• Satisfaction with clinical services</li> </ul>	<ul style="list-style-type: none"> <li>• Knowledge of the disease and strong willingness to be cured.</li> <li>• Received food supplement</li> <li>• Followed nurse's instruction</li> <li>• Satisfied with clinical services</li> <li>• Symptomatic improvement</li> </ul>	<ol style="list-style-type: none"> <li>1. Knowledge about TB treatment</li> <li>2. Food incentives</li> <li>3. Symptomatic improvement</li> <li>4. Good patient/clinic staff relations</li> </ol>

# WHAT DO WE FOUND- continue

- Some of those interviewed in Ermera believed that modern medicine doesn't work unless the ritual ceremony named “*sakit ain iha mota*” is performed by a traditional priest (*kuku*). For others traditional medicine was seen as the only appropriate treatment, and this a common reason for defaulting in this rural district.

*Firstly, when I got this disease I went to the clinic for treatment and after two weeks I realized my condition did not improve. Then the nurse asked me to stay there for eight months and I refused. I have a cousin who had previously suffered from the same disease and recovered well by taking traditional medicine.*

Defaulter, Ermera

The use of traditional treatment was widely reported by community members in both districts, and participation in traditional ceremonies designed to treat “*Mear Ran*” was observed by the research team.

# WHAT DO WE FOUND-continues

## *Access to quality TB services*

- Some patients said they were forced to discontinue treatment because their condition had deteriorated.

Could not walk. ; TB health worker rarely to visit patients' homes

- Interference with their ability to meet their daily obligations & Financial disincentive :  
working/ attending school, The restricted hours of the clinic, the long wait,

Financial disincentives included loss of income as well as direct transport costs involved in attending the clinic. It was a frustrating issue for TB nurses, and was raised frequently by community members.

*We said transportation because each time patients visit the clinic, they have to pay a return cost for transportation and when they get there, they were only allowed to swallow drugs in front of the nurse. And then, the patients were asked to return the next day for the same reason.*

Community member, Ermera

- The re-imburement of transport costs and the provision of supplementary food were important enabling factors identified by completers in Ermera.

## Local terms associated with TB symptoms.

Local symptoms definition	Modern term	Causes	Treatment Options
<i>Mear Mutin</i>	Dry cough	Too much cigarettes smoking	Cough medicine or traditional remedies
<i>Mear Tasak</i>	Cough with sputum	Too much cigarettes smoking Germ	Cough medicine or traditional remedies
<i>Mear/muta Ran</i>	Haemoptysis	Family sins Germs	Traditional ceremony ( <i>sakit ain</i> ) Modern treatment
<i>Paru-paru basah</i>	Pleural effusion	Sleep on wet floor/humid	Modern treatment
<i>Hirus matan moras</i>	Chest pain	Lifting a heavy weight/ heavy work	Modern medicine or traditional remedies

# HOW RELEVANT THE FINDINGS

- **Global : Conform studies in other countries**
- This study reveals the importance of strengthening health education to increase community awareness and knowledge about TB, in order to address local beliefs.
- Lack of understanding about the cause and treatment of TB to be a pivotal issue <sup>11-23</sup>,
- Vietnam similarly identified the belief that TB is hereditary, and thereby stigmatic.<sup>24</sup>
- *Discontinued treatment intentionally due to the false perception that they have been cured* <sup>,15,20,22,23,25-28</sup>
- Understanding patients' beliefs, reflected in the terms they use for TB, can be very helpful in finding ways to overcome misunderstandings which deter patients from completing treatment.<sup>11</sup> These will vary from region to region, even in a small country such as Timor Leste, which is why it is important that studies such as this identify them.
- Other factors contributing to the decisions patients. For indigenous Bolivians, the social dimensions of health care delivery in marginalised populations.<sup>29</sup> In Haiti, patients' aetiological beliefs do not predict their adherence with chemotherapy.<sup>30</sup>

# HOW RELEVANT THE FINDINGS

- Access to quality health care is key to addressing poor adherence to TB treatment (re: inconvenient clinic times, ethnic discrimination, and prior maltreatment by health care services as the major reasons for non-adherence. <sup>8,13-15,25,27-29</sup>

# Local context

- Positive about their experience with clinic staff, incentives such as reimbursement of transport costs and the provision of supplementary food, Decentralising DOTS services to improve access to TB treatment
- In Timor Leste, issues of economic difficulties and geographical remoteness : strengthening previous strategies such as *alburgues* (hostels) , and offering treatment at satellite/mobile clinics, with training of more community workers.<sup>6</sup>
- In addition, the Ministry of Health is leading the way in decentralization of government services and increasing community involvement in planning and delivery through their “integrated community health service”, with TB services as one of the major components of this plan ( SISCa).

# Conclusion

- Local cultural beliefs, socio-economic obstacles and health services inability to provide patients with easy access to quality services, contribute to non-adherence to TB treatment.
- This study has assisted the TB control program in Timor Leste to modify DOTS expansion strategies to overcome some of the treatment completion barriers. By highlighting the importance of listening to the community and their concerns, community involvement in the program has been encouraged.
- There are now regular meetings with and involvement of community groups in identifying possible TB patients and assisting them during treatment.
- Further research is needed to examine the local barriers and to inform the development of locally-based strategies in other districts, in order to improve the treatment completion rate throughout Timor Leste.

# ACKNOWLEDGMENT

- We thank the participants, research assistants, Minister for Health, NTP Director and staff for their support. N Martins was supported by the UNICEF/UNDP/World Bank/WHO Special Program for Research and Training in Tropical Diseases (TDR). P Kelly was supported by the National Health and Medical Research Council (Australia).
- For the University of SYDNEY, Prof Robinson, Dr Dilhani, and everyone present here today.

## REFERENCES

- 1 WHO. Global tuberculosis control: surveillance, planning, financing. WHO Report 2007. Geneva: World Health Organization, 2007
- 2 Volmink J, Garner P. Directly observed therapy for treating tuberculosis. *Cochrane.Database.Syst.Rev.* 2006; 19:CD003343
- 3 WHO. Treatment of Tuberculosis : Guidelines for National Programmes. 3rd ed. Geneva: WHO, 2003
- 4 Pope DS, Chaisson RE. TB treatment: as simple as DOT? *INT J TUBERC DIS* 2003; 7:611-615
- 5 Drabo KM, Dauby C, Coste T, et al. Decentralising tuberculosis case management in two districts of Burkina Faso. *INT J TUBERC LUNG DIS* 2006; 10:93-98
- 6 Martins N, Heldal E, Sarmento J, et al. Tuberculosis control in conflict-affected east timor, 1996-2004. *Int J Tuberc Lung Dis.* 2006; 10:975-981
- 7 Munro SA, Lewin SA, Smith HJ, et al. Patient adherence to tuberculosis treatment: a systematic review of qualitative research. *PLoS Med* 2007; 4:e238
- 8 Khan A, Walley J, Newell J, et al. Tuberculosis in Pakistan: socio-cultural constraints and opportunities in treatment. *Soc.Sci.Med* 2000; 50:247-254
- 9 CIA. The world fact book: Timor Leste. Washington, 2007
- 10 Liamputpong P, Ezzy D. *Qualitative Research Methods (2nd Edition)*. Melbourne: Oxford University Press, 2005
- 11 Banerjee A, Harries AD, Nyirenda T, et al. Local perceptions of tuberculosis in a rural district in Malawi. *Int J Tuberc Lung Dis.* 2000; 4:1047-1051
- 12 Demissie M, Getahun H, Lindtjorn B. Community tuberculosis care through "TB clubs" in rural North Ethiopia. *Soc Sci Med* 2003; 56:2009-2018
- 13 Edginton ME, Sekatane CS, Goldstein SJ. Patients' beliefs: do they affect tuberculosis control? A study in a rural district of South Africa. *Int J Tuberc Lung Dis* 2002; 6:1075-1082
- 14 Harper M, Ahmadu FA, Ogden JA, et al. Identifying the determinants of tuberculosis control in resource-poor countries: insights from a qualitative study in The Gambia. *Trans R Soc Trop Med Hyg* 2003; 97:506-510
- 15 Johansson E, Long NH, Diwan VK, et al. Attitudes to compliance with tuberculosis treatment among women and men in Vietnam. *Int J Tuberc Lung Dis* 1999; 3:862-868
- 16 Johansson E, Winkvist A. Trust and transparency in human encounters in tuberculosis control: lessons learned from Vietnam. *Qual Health Res* 2002; 12:473-491
- 17 Liefoghe R, Baliddawa JB, Kipruto EM, et al. From their own perspective. A Kenyan community's perception of tuberculosis. *Tropical Medicine and International Health* 1997; 2:809-821
- 18 Liefoghe R, Michiels N, Habib S, et al. Perception and social consequences of tuberculosis: a focus group study of tuberculosis patients in Sialkot, Pakistan. *Soc Sci Med* 1995; 41:1685-1692
- 19 Marra CA, Marra F, Cox VC, et al. Factors influencing quality of life in patients with active tuberculosis. *Health Qual Life Outcomes* 2004; 2:58
- 20 Nair DM, George A, Chacko KT. Tuberculosis in Bombay: new insights from poor urban patients. *Health Policy Plan* 1997; 12:77-85
- 21 Tekle B, Mariam DH, Ali A. Defaulting from DOTS and its determinants in three districts of Arsi Zone in Ethiopia. *Int J Tuberc Lung Dis* 2002; 6:573-579
- 22 Wares DF, Singh S, Acharya AK, et al. Non-adherence to Tuberculosis treatment in the eastern Tarai of Nepal. *INT J TUBERC LUNG DIS* 2003; 7:327-335
- 23 Watkins RE, Rouse CR, Plant AJ. Tuberculosis treatment delivery in Bali: a qualitative study of clinic staff perceptions. *INT J TUBERC DIS* 2004; 8:218-225
- 24 Long NH, Johansson E, Diwan VK, et al. Different tuberculosis in men and women: beliefs from focus groups in Vietnam. *Soc Sci Med.* 1999; 49:815-822
- 25 Jaiswal A, Singh V, Ogden JA, et al. Adherence to tuberculosis treatment: lessons from the urban setting of Delhi, India. *Trop Med Int Health* 2003; 8:625-633
- 26 Menegoni L. Conceptions of tuberculosis and therapeutic choices in Highland Chiapas, Mexico. *Med Anthropol Q* 1996; 10:381-401
- 27 Sanou A, Dembele M, Theobald S, et al. Access and adhering to tuberculosis treatment: barriers faced by patients and communities in Burkina Faso. *Int J Tuberc Lung Dis* 2004; 8:1479-1483
- 28 Watkins RE, Plant AJ. Pathways to treatment for tuberculosis in Bali: patient perspectives. *Qual Health Res* 2004; 14:691-703
- 29 Greene JA. An ethnography of nonadherence: culture, poverty, and tuberculosis in urban Bolivia. *Cult.Med Psychiatry.* 2004; 28:401-425
- 30 Farmer P. Social scientists and the new tuberculosis. *Soc Sci Med.* 1997; 44:347-358
- 31 Liefoghe R, Suetens C, Meulemans H, et al. A randomised trial of the impact of counselling on treatment adherence of tuberculosis patients in Sialkot, Pakistan. *Int J Tuberc Lung Dis.* 1999; 3:1073-1080
- 32 Malotte CK, Hollingshead JR, Rhodes F. Monetary versus nonmonetary incentives for TB skin test reading among drug users. *Am.J Prev.Med.* 1999; 16:182-188
- 33 Tulsy JP, Hahn JA, Long HL, et al. Can the poor adhere? Incentives for adherence to TB prevention in homeless adults. *Int J Tuberc Lung Dis.* 2004; 8:83-91