

**Access to Tuberculosis Treatment for Migrant and Refugee Populations in Tak province,
Thailand**

Naomi Tschirhart

**Thesis Supervisor: Dr. Angel M. Foster
Thesis Co-supervisor: Prof. François Nosten**

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Glossary of Acronyms

AMI	Aide Médicale Internationale
ASEAN	Association of Southeast Asian Nations
AEC	ASEAN Economic Community
BPHWT	Back Pack Health Worker Team
CHVs	Community Health Volunteers
CHWs	Community Health Workers
CMHI	Community Migrant Health Insurance
DFID	UK Department for International Development
DOT	Direct Observed Treatment
FGD	Focus Group Discussion
GIS	Geographic Information System
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome
IDRC	International Development Research Centre
IOM	International Organization for Migration
KDHW	Karen Department of Health and Welfare
MSH	Mae Sot Hospital
MSF	Médecins Sans Frontières
MTC	Mae Tao Clinic
MDR-TB	Multidrug-resistant Tuberculosis
MOPH	Thai Ministry of Public Health
NGOs	Non-governmental Organizations
PHSS	Public Health Surveillance System
PU-AMI	Première Urgence - Aide Médicale Internationale
SSS	Social Security Scheme
SMRU	Shoklo Malaria Research Unit
Tak PHO	Tak Public Health Office
TB	Tuberculosis
TB/HIV	Tuberculosis and Human Immunodeficiency Virus Co-infection
TTBI	Tak Tuberculosis Initiative
UNHCR	United Nations High Commissioner for Refugees
USAID	United States Agency of International Development
VHW	Village Health Worker
WVT	World Vision Thailand
XDR TB	Extensively drug-resistant Tuberculosis

Access to Tuberculosis Treatment for Migrant and Refugee Populations in Tak province, Thailand

Abstract

Objectives: The aim of this project was to examine tuberculosis (TB) treatment access among migrant and refugee populations in a Thai border province. To study TB control from a wider perspective, we also sought to understand how migrant and refugee cases are enumerated in the public health surveillance system and explored treatment providers' responsiveness to treatment barriers.

Methods: We used a concurrent mix-methods design with an overarching qualitative emphasis and an embedded smaller quantitative survey. To gain perspectives on treatment accessibility we conducted focus group discussions with TB, tuberculosis and human immunodeficiency virus co-infection (TB/HIV) and multidrug-resistant tuberculosis (MDR-TB) patients. We also held key informant interviews with TB treatment providers and public health officials in Tak province and did a survey of community health volunteers. We analyzed the data using thematic analysis and descriptive statistics.

Results: We found that migrants are travelling long distances with active TB to seek treatment in Tak province and that legal status influences migrants' eligibility for TB care. Migrants in our study reported more barriers to accessing TB treatment than refugees. TB/HIV and MDR-TB treatment options for migrants in Tak province are limited and are heavily reliant on donor funding. We found that migrant and refugee TB cases are under reported in the public health surveillance system. Organizations in Tak province are highly collaborative and we identified two NGOs who have developed programs that are responsive to migrants' needs.

Conclusions: Our research suggests that in Tak province, Thailand access to TB treatment occurs at the intersection of health system accessibility, population ability and legal status. Interventions to improve treatment access and adherence to TB treatment necessarily extend outside of the healthcare system and address the social determinants of health.

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Contributions of Co-Authors and Collaborators

My co-authors and collaborators made important contributions to this thesis project. Dr. Angel Foster, my supervisor, oversaw the project and contributed to the study conceptualization and design, implementation, and interpretation of the findings. Dr. Foster and I met regularly to discuss the project and she provided extensive advice throughout my PhD studies. Dr. Foster also edited this thesis. Prof. François Nosten, my co-supervisor, contributed to conceptualization and design of the project, participated in its design, oversaw data collection and contributed to the interpretation of the findings. My thesis proposal committee members, Dr. Louise Bouchard, Dr. Ronald Labonté and

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As the principal investigator, I was responsible for all phases of the project, including study design, data collection and analysis, and interpretation of the findings. I am the primary author of all of the articles contained in this thesis and wrote the first drafts.

We obtained research ethics approval for this study from the Health Sciences and Sciences Research Ethics Board at the University of Ottawa (File #H02-14-08), the Oxford Tropical Research Ethics Committee at the University of Oxford (538-14) and the Tak Provincial Public Health Office (TK 1/2557).

Dedication

I dedicate this thesis to the migrant and refugee TB patients who participated in our project and to my husband, Channarong Intahchomphoo and my son Gabriel Ravee for their endless support.

INTRODUCTION

Infectious diseases are easily transmitted across national borders and thus pose an international threat to human health. In Thailand's Tak province, high rates of tuberculosis (TB) along the Thailand-Myanmar¹ border have been linked to refugee and migrant populations. At present, it is difficult to estimate the prevalence of TB, multi drug-resistant TB (MDR-TB) and tuberculosis and human immunodeficiency virus co-infection (TB/HIV) in this population. Multidrug-resistant tuberculosis is caused by bacterial strains that do not respond to standard first line drug treatment and require prolonged treatment that is 100 to 300 times more expensive than regular TB treatment (Wells et al., 2007). Having a previous case of TB is a risk factor for developing MDR-TB. There are concerns that these cases can become extensively drug-resistant (XDR). XDR TB is highly infectious and almost untreatable (Wells et al., 2007). XDR TB cases have been reported in both Myanmar and in Thailand (Chuchottaworn, 2010; World Health Organization Country Office Myanmar, 2012).

Conducting surveillance² and treating infectious disease among mobile migrant populations presents a unique set of challenges related to population movement, legal status, and financial barriers to healthcare access. In Tak province, non-governmental healthcare providers, and community groups have stepped in to address these challenges. Engagement in migrant health has extended to the community level where community health workers and volunteer health workers provide health services unrelated to TB on

¹ This project uses the term "Myanmar" to refer to the country bordering Thailand's northwestern region. The term Myanmar was chosen as it is the official name sanctioned by the national government and the

² In defining surveillance I have chosen the definition developed the Institute of Medicine (2007), specifically that builds upon the work of John Last (1995) and the World Health Organization (2000). Surveillance is "the continual scrutiny of all aspects of occurrence and spread of a disease that are pertinent to effective control" and involves the "systematic collection, analysis, interpretation, and dissemination of health data" (IOM, 2007).

both sides of the Thailand-Myanmar border (International Organization for Migration & Ministry of Public Health, 2009; Lee et al., 2009; Sirilak et al., 2013).

TB is curable but requires treatment. Identifying pathways to treatment and associated difficulties can be useful in developing interventions to improve access. In this thesis I examine TB treatment accessibility, public health surveillance system (PHSS)³ and health system responsiveness using data we collected from migrant and refugee TB patients, public health officials, health care providers, and community health volunteers.

This project contributes to the advancement of knowledge in the field of population health by identifying challenges and opportunities for improved infectious disease treatment and surveillance among mobile migrant populations. Research results can be used to inform future population level interventions along the Thailand-Myanmar border or in other similar geographic contexts.

Defining Migrants

For this project a migrant is defined as an individual who has resided in a foreign country for more than one month or who has crossed a national border to access essential services, irrespective of the causes, voluntary or involuntary and the means, regular or irregular used to migrate. Individuals who have received refugee status are not considered migrants. This description is adapted and modified from a definition used by the International Organization for Migration (2017), with the adaptation to include

³ In this thesis I use public health surveillance system to refer to the network of partners and resources that support surveillance activities. The US Center for Disease Control defines a public health surveillance system as “everything that supports the activity of collecting and monitoring disease data, including policies, laws, people, partners, information systems, processes, and resources at the local, state, and national levels” (2014).

individuals who come across the border simply to access services. These migrants could be referred to as cross border migrants, given that they live in Myanmar. However, I found that in this context there is a significant amount of fluidity between cross border migrants and foreign labour migrants living in Thailand as their status may fluctuate between these two categories. Throughout the thesis I use the phrases “documented” and “undocumented” to refer to whether migrants have the required documentation to travel and work in Thailand.

Rationale and Objectives

Research from Tak province and other jurisdictions in Thailand has shown that migrants have difficulties accessing TB healthcare services and adhering to treatment (Minetti et al., 2010; Naing, Geater, & Pungrassami, 2012). Treatment for TB treatment can be lifesaving while reducing the persons’ infectiousness and the likelihood that he/she will transmit TB to someone else. Adherence to treatment also reduces the risk of developing subsequent drug resistant TB. In Tak province, TB disproportionately impacts migrants and refugees (Hemhongs, 2008). Previous research has not explored how migrant and refugee patients access TB treatment along the Thailand-Myanmar border. I anticipate that understanding the processes through which these groups access treatment, as well as the associated barriers, can help to identify opportunities to improve treatment access.

Identifying new and existing cases of disease is an important function of public health surveillance. Documented incidence and prevalence of disease are used to quantify the problem and often factor into discussions on public health resource allocation.

Isolating how TB cases enter into the surveillance system can help to clarify which sub populations are included in the PHSS figures as well as who is excluded.

Within Tak province, various healthcare actors (inclusive of the Tak provincial public health department, international organizations, community based organizations and community health workers) have mobilized to provide TB treatment services. Treatment providers record case level TB data. Based on their experience implementing TB treatment and/or surveillance programs, we predicted that they also identified treatment/surveillance barriers and that they may have adjusted their programs accordingly. We anticipated that examining healthcare system, PHSS, and community responsiveness⁴ to the identified barriers would provide valuable information on the approaches that have been utilized. We chose to collect responsiveness data, in addition to the barriers identified by TB patients, to create a more nuanced analysis inclusive of recommendations to further address treatment and surveillance barriers.

This thesis has four objectives:

1. To identify the processes through which migrants and refugees access TB treatment in Tak province;
 2. To examine TB treatment accessibility with an emphasis on barriers and enabling factors;
 3. To document how migrant and refugee TB cases are accounted for in the PHSS;
- and

⁴ Responsiveness has been utilized in the health systems literature in regard to the non-health enhancing and non-financial features of the system. Da Silva (2000) explains that a responsive health system responds appropriately to legitimate individual expectations. Da Silva (2000) describes that responsiveness is linked to patient satisfaction questionnaires. In this doctoral research project, the term responsiveness is used to describe adaptations and actions that have been made in response to perceived barriers to TB treatment and surveillance. Here responsiveness is not limited to the non-health enhancing and non-financial features of the system.

4. To examine the responsiveness of community and non-governmental healthcare providers and public health officials to treatment and surveillance barriers.

Research Questions

The research questions follow the stated objectives:

1. How do refugees and migrants from Myanmar access TB, TB/HIV and MDR-TB treatment in Tak province, Thailand?
2. What are the barriers and enabling factors for TB treatment access?
3. How are migrant and refugee TB cases enumerated in the Public Health surveillance system in Tak province?
4. How have community and non-governmental healthcare providers and public health officials responded to treatment and surveillance barriers?

Literature Review

Given that the literature on TB and migrant populations in Thailand's Tak province is limited we decided not to conduct a systematic review but instead began by reviewing literature that was relevant to TB in the border region and then examined the wider literature for overarching related themes. We also examined the grey literature for relevant NGO reports. Here, the literature review is presented in three parts and spans from the local context to broader themes of TB, social determinants of health, and migration. The first section introduces the research context and provides an overview of research conducted along the Thailand-Myanmar border on TB, TB/HIV, and community health workers and volunteers. A brief discussion is provided on the gaps in the literature related to TB treatment and surveillance in this specific region. The second section

highlights broader implications for TB related to drug resistance and HIV co-infection.

The third part addresses larger themes of social determinants and migration and their relationship with TB.

Part I: Thailand-Myanmar Border Research Context and Healthcare Organization

This research project is situated in Tak province northwestern Thailand which borders Kayin (Karen) state, Myanmar (see Appendice A for map). Kayin state is a mountainous area predominantly populated by the Karen, an ethnic minority hill tribe population. While there are distinct subgroups of Karen with different languages, pan-Karen identity has been structured by the shared experience of “structural opposition” to the national government (Cheesman, 2002). Seeking autonomy, Karen groups engaged in guerilla style warfare that spanned almost seven decades and only recently ended with a ceasefire agreement signed by the Karen National Union on October 15, 2015 (Slodkowski, 2015).

The current state of healthcare in Karen state is linked to the legacy of civil war and the associated government policies. Under the “four cuts policy” of Myanmar’s former national government (State Peace and Development Council), ethnic regions including Karen state were cut off from food, funding, supplies and information (Center for Public Health and Human Rights, John Hopkins Bloomberg School of Public Health, 2016). As a result of this policy, during the conflict period healthcare infrastructure and healthcare services provided by the national government were not available in Kayin State. While not officially recognized by the national Myanmar government, the Karen have their own government structure, the Karen National Union, with departments that

provide some services to the Karen population living in Karen State. The Karen Department of Health and Welfare (KDHW) provides some healthcare services and relies on donor funding and partnerships with international organizations to conduct its work. Partnership organizations include Aide Médicale Internationale (AMI), the Back Pack Health Worker Team (BPHWT), the International Committee of the Red Cross, the International Rescue Committee, and the Shoklo Malaria Research Unit (SMRU); several of these organizations provide direct patient care in Kayin State (Karen Department of Health and Welfare., 2015). There are indications of possible future collaboration between the national government and the KDHW as official representatives from each group met in 2013 and the KDHW subsequently indicated that there is a potential to work together to improve the healthcare system in Karen state (Shaung, 2013).

Academic literature describing the status of the healthcare system and population level health within Karen State is limited. A population based survey of internally displaced persons in eastern Myanmar, specifically Kayin state and Karenni state, found under five child mortality to be 218 per 1,000 live births (Mullany et al., 2007). The Lancet reported that Myanmar has some of the poorest overall health indicators worldwide, with a life expectancy of 56 years, high out of pocket health expenditures on health (81%) and worse health indicators for ethnic minorities (The Lancet, 2012).

In Tak province, the healthcare system is fragmented with multiple providers providing services to different populations. Healthcare access is strongly linked to legal status. As a result of the fighting inside Myanmar, tens of thousands have fled the country and took up longstanding residence in refugee camps in Tak province, Thailand and other bordering provinces. In December 2015 there were 61,889 UNHCR verified refugees

living in Tak province's three refugee camps, Mae La, Umpiem Mai and Nu Po (The Border Consortium, 2015). There are also six additional refugees camps along the Thai-Myanmar border in Mae Hong Son, Kanchanburi and Ratchaburi provinces (The Border Consortium, 2015). Thailand did not sign the 1951 Refugee Convention and does not accept asylum seekers. However the country has permitted refugees to remain on a temporary basis in gated camps along the Thailand-Myanmar border (United Nations High Commissioner for Refugees, 2015). Registered refugees are able to access healthcare in the camp that is delivered by foreign medical organizations. Première Urgence - Aide Médicale Internationale (PU-AMI) provides care in the refugee camps in Tak province. Refugee camps offer a stable environment for treatment and follow up and at least one study has confirmed that tuberculosis treatment outcomes are better for camp refugees than for migrants and local Thai villagers (Minetti et al., 2010).

For migrants in Thailand, access to healthcare has traditionally been closely tied to registration processes. In 2009, as part of the National Verification Program, registered migrants were able to have 4% of their salaries deducted in exchange for a social security scheme (SSS) card that would provide them access to the universal healthcare system at a cost of 30 baht (CAD1) per visit (Sandar Oo, 2013). The 4% paid by the employee was to be matched by an equal contribution from the employer (Sandar Oo, 2013). However, some employers did not want to make the required financial contribution and didn't register their migrant employees (Sandar Oo, 2013). To supplement the SSS, the Thai government introduced a Community Migrant Health Insurance (CMHI) scheme in 2001 which enrolls migrants subject to health screening (Guinto, Zuwasti Curran, Suphanchaimat, & Pocock, 2015). While in September 2013 the Thai government

announced a new process for migrants to access CMHI whereby migrants would be able to register themselves using fingerprints and photo identification, in reality some hospitals deterred undocumented migrants (Guinto et al., 2015; The Nation, 2013). The yearly costs of the CMHI plans in 2013 were 365 baht (CAD12) for children, 2,200 baht (CAD73) for adults plus 600 baht (CAD20) for exams (The Nation, 2013).

Migrants who arrive in Thailand without documentation and do not have a work permit are unable to access the low cost treatment at Thai hospitals that is available to migrants with work permits. For a select few wealthy individuals, cost is not an issue and they can pay to receive treatment at the Thai government or private hospitals. However, most undocumented migrants cannot afford to pay for treatment given their low wages. Labour migrants in the Thai border town of Mae Sot often receive less than the national minimum daily wage 300 baht (CAD11) and may receive as low as 150-180 baht (CAD 6-7) (Jaisat, Biel, Pollock, & Press, Brahm, 2014). As a response to the gap in service provision for undocumented migrants, community and international organizations have opened clinics that provide free healthcare to migrants. These clinics rely on foreign donor funding for their operational expenses. The Mae Tao Clinic (MTC), established in 1989 by Dr. Cynthia Muang is the largest of these types of clinics in Tak province and provides healthcare to 150,000 persons a year (Mae Tao Clinic, 2013). Treatment at MTC is largely provided by medics who have received specialized medical training to perform specific tasks with a much narrower scope of practice than a doctor. Mae Tao Clinic does not currently treat TB cases but provides referrals to other health care providers. SMRU provides treatment for TB in its two TB residential treatment centers along the border, one in Kayin State, Myanmar and the second in Tak province, Thailand. The Tak

Tuberculosis Initiative (TTBI) was formed in 2011 as a consortium between SMRU, PU-AMI, Tak Public Health Office (Tak PHO), and the International Organization for Migration (IOM). TTBI is supported by the United Kingdom's government Department for International Development (DFID). Consortium members are the main source of TB treatment for unregistered migrants and refugees in Tak province. The healthcare system in Tak province is highly fragmented with care provided by diverse providers.

Community health workers and volunteers in Thailand and Myanmar

Along the Thailand-Myanmar border, beyond the formal system there exists a range of semi-skilled practitioners who provide basic healthcare to refugees and migrants. These providers include community and volunteer healthcare workers, medics, traditional birth attendants, and traditional health practitioners. Community health workers (CHWs) are paid workers who are differentiated from other health professionals such as doctors and nurses by the shortened period of training they receive as well as their narrow scope of practice (World Health Organization, 2007). Community health volunteers (CHVs) are unpaid volunteers who provide referrals and other primary health care services at the community level. While not included in the World Health Organization definition of CHWs, Bodeker and Newman (2012) argue that traditional health practitioners play an important role in this region given that, due to scarce resources, Karen traditional medicine is the primary healthcare system that is available to many ethnic minorities living inside eastern Myanmar (2012). TB was identified as one of the priority conditions treated by Karen ethnic traditional health practitioners (Bodeker & Neumann, 2012).

Inside Myanmar, the use of CHWs and CHVs can be linked to attempts to improve healthcare despite a weak national health system. In 2000, the World Health Organization rated Myanmar's healthcare system as 190 out of 191 countries (World Health Organization, 2000). The BPHWT was created in 1998 to help provide mobile health services to eastern Myanmar and other ethnic regions. BPHWT backpack health workers are trained CHWs who provide referrals, treat common illnesses, and provide medicine (Back Pack Health Worker Team, 2015). In 2015, BPHWT reported over 1,300 health workers in their target zones in Myanmar (Back Pack Health Worker Team, 2015). Acute respiratory infections are among the illnesses most commonly treated by BPHWT with 6,585 mild and 2, 223 severe cases treated in the first half of 2015 (Back Pack Health Worker Team, 2015). In this time frame BPHWT provided treatment to 197 suspected TB patients 12 of which were under five years old (Back Pack Health Worker Team., 2015).

A study by Lee et al. (2009) documented partnerships with village health workers that helped scale up a malaria program inside conflict areas in eastern Myanmar. Completed in conjunction with the BPHWT, CHWs trained local villagers to take on the role of Village Health Workers (VHWs) (Lee et al., 2009). VHWs helped to address the shortage of skilled healthcare workers in rural and remote areas and allowed clinic workers to focus on more challenging aspects of care provision (Lee et al., 2009). For example, VHWs managed Direct Observed Treatment (DOT) for Malaria treatment, which is a protocol used to ensure patients take their medication(s) (Lee et al., 2009). Lee et al. suggested that the VHWs also play an important role in disease surveillance as they live in the communities and are able to respond to an outbreak (2009). The authors

propose that VHWs could be an initial first step in the development of an infectious disease surveillance system in eastern Myanmar (Lee et al., 2009). On the Thai side of the border, migrants have been used as health volunteers in the provision of primary-healthcare to other migrants (Sirilak et al., 2013). The use of unpaid migrants as health volunteers in Thailand is related to challenges migrants face accessing healthcare (International Organization for Migration & Ministry of Public Health, 2009). Sirilak et al. (2003) conducted a qualitative study examining migrants' experiences as volunteers in the *Migrant Health Volunteer Program* that had been created by the Ministry of Public Health (MOPH) of Thailand and the International Organization for Migration with funding from the United States Agency for International Development (USAID). The initiative was designed so that volunteers would serve as communicators between migrant communities and health officials as well as community educators. The study found that migrant volunteers generally assisted in the provision of primary healthcare services, and were sometimes asked to assist with other district health priorities. In Tak province, volunteers were approached to help with infectious disease surveillance and in another province some volunteers provided DOT for tuberculosis (Sirilak et al., 2013).

An underlying rationale of the Thai government's *Migrant Health Program* is that providing health services to migrant populations in Thailand is a necessary step in protecting the health of the Thai population. The *Border Health Development Master Plan, 2007-2011* developed by the Ministry of Public Health links migrant health to security and states, "poor health condition affects country's [*sic*] economy and national security" (International Organization for Migration & Ministry of Public Health, 2009, p. 96).

TB in Thailand and Myanmar

Both Thailand and Myanmar are listed among the 22 high TB burden countries. The disease burden is higher in Myanmar, with prevalence estimated at 457/100,000 in 2014 compared to a prevalence of 160/100,000 in Thailand (World Health Organization, 2015a). Estimated new cases of TB were similarly higher in Myanmar (369/100,000) than Thailand (120/100,000) (World Health Organization, 2015a). Of the new TB cases in 2014, 5% of the cases in Myanmar and 2% in Thailand were multidrug resistant (World Health Organization, 2015a). In Myanmar more than a quarter (27%) of the TB retreatment cases were multidrug resistant compared with less than one fifth (19%) in Thailand (World Health Organization, 2015a). While estimates for TB/HIV co-infection are close between Thailand (13%) and Myanmar (11%), HIV status is known for fewer patients in Myanmar (40%) than Thailand (71%) (World Health Organization, 2015a). Rates for TB mortality excluding TB/HIV are five times higher in Myanmar (53/100,000) than Thailand (11/100,000) (World Health Organization, 2015a). Mortality for TB/HIV is slightly higher in Myanmar (8/100,000) compared to Thailand (7/100,000). These data⁵ suggest that Myanmar is more heavily burdened by TB, TB/HIV and MDR-TB than Thailand.

While estimated national figures provide a useful proxy, annual prevalence data for TB in Tak province among migrants and refugees is difficult to ascertain. Historically surveillance data in Tak province has been fragmented, as the Thai National TB program does not have a system to receive data from different non-governmental organizations

⁵ These figures are taken from the Global Tuberculosis Report 2015 produced by the World Health Organization and provide estimated figures only. Based on reported populations of 53 million in Myanmar and 68 million in Thailand and the presented prevalence and incidence figures, Myanmar has a greater TB, TBHIV and MDR-TB burden.

(NGOs) that provide healthcare in the province and does not uniformly collect data on non-Thais (Hemhongsra et al., 2008). In 2007 a demonstration project was undertaken whereby public health staff actively contacted medical professionals to request case finding information (versus passive), individual patient data was collected (versus statistics), and cases diagnosed in non-Thais or in persons diagnosed in a non-governmental facilities were included (Hemhongsra et al., 2008). This project found more new cases diagnosed among refugees⁶ (340/100,000) and migrants (150/100,000) than Thai villagers (109/100,000) (Hemhongsra et al., 2008). Funding for this enhanced TB surveillance system in Tak province has been discontinued (key informant, personal communication). However surveillance data can be extremely useful for quantifying the magnitude of the TB burden among migrants and refugees in Tak province as well as to identify treatment success and default rates. Jaruwaree Snidwongse, project manager of a TB program with World Vision Foundation Thailand identifies the need for prevalence data,

TB prevalence is particularly difficult to assess because of the transient nature of migrant workers in these areas...and it is critically important that we do because TB deaths are rising as the bacteria becomes immune to existing treatments. (World Vision Foundation of Thailand, 2012, para 10).

The published literature on TB among migrants and refugees in Tak province is limited. I located a report, two epidemiological studies and two articles on TB control among migrant populations that are specific to Tak province. In a 2008 report, TB was cited by the Tak provincial public health department as one of the most important

⁶ Refugees who are preparing to move to a third country are automatically screened by IOM. This active screening contributes to higher numbers of diagnosed TB cases in refugees.

diseases among the province's 120,593 registered Burmese migrant workers (Aeumrod, 2008). Iemrod & Kavinum (2015) reported that between 2006-2011 most of the provinces' TB cases were in the Mae Sot district area of which more than half were among non-Thais. Mae Sot city is the largest urban area close to the Myanmar border in Tak province. The article included general recommendations for TB control improvement that were not specific to migrant populations (Iemrod & Kavinum, 2015).

Hemongsa et al. (2008) conducted an epidemiological study to measure the burden of TB, HIV/TB and MDR-TB in Tak province. The study found a higher percentage of TB cases among non-Thais (65%) than among Thais (Hemhongsa et al., 2008). The trend was similar for MDR-TB, for which 70% of the cases were diagnosed among non-Thais (Hemhongsa et al., 2008). The study suggested that MDR-TB in Tak province is being driven by cases from Myanmar as six cases of MDR-TB were found among migrants who had not previously sought treatment, compared to zero among first time Thai tuberculosis patients (Hemhongsa et al., 2008). Hemongsa et al. (2008) also identified "medical migrants" who live in Myanmar but come to Thailand for TB treatment. A 20-year retrospective study along the Thailand-Myanmar border by Minetti et al. (2010) found that TB treatment outcomes were better for refugees living in camps than for Burmese migrants or Thai villagers. The study discovered that migrants reached treatment once their disease was at an advanced stage and recommended a patient-centered approach be implemented to improve treatment outcomes (Minetti et al., 2010).

From a health systems perspective, Kaji et al. (2015) conducted qualitative interviews with health care providers and public health officials on both sides of the Thai-Myanmar border and identified significant challenges for TB control coordination and

collaboration namely: limited resources and staff capacity, loss to follow up among migrants and ensuing MDR-TB cases, and patients' poor socio economic conditions (Kaji, Thi, Smith, Charunwatthana, & Nosten, 2015). Interviewees articulated concerns about service delivery sustainability as international organizations provide TB treatment for migrants in this region and there could be a potential service gap if the NGOs discontinue their TB programs (Kaji et al., 2015). The authors recognized a need for a more structured referral mechanism to refer patients between countries (Kaji et al., 2015). In addition, Kaji et al. (2015) identified potential interventions that could help migrants access TB treatment specifically: free treatment, transportation, food, income during treatment and coordination between health officials and law enforcement to allow migrants to travel for treatment.

I located two articles on TB among migrant populations in other Thai provinces. Naing et al. (2012) conducted a survey of health seeking behaviours among migrant factory workers, rubber tappers, and construction workers in the southern Thai province of Songkla. Having legal status was associated with a greater use of government healthcare facilities (Naing et al., 2012). The study found that migrant workers' first health seeking behavior for TB symptoms was to self-medicate with inappropriate drugs including steroids (Naing et al., 2012). Workers explained that they were waiting to see if their symptoms worsened before seeking treatment (Naing et al., 2012).

Like Tak, Sangklaburi is a Thai province that borders Myanmar. A qualitative study conducted with migrant communities in Sangklaburi identified research on MDR-TB prevalence as an important future research topic (Ditton & Lehane, 2009). The study indicated that TB, as a chronic condition, was often left untreated (Ditton & Lehane,

2009). Early detection, and adequate treatment were identified as challenges for children and elderly individuals (Ditton & Lehane, 2009). Stakeholders in Ditton and Lehane's (2009) research project agreed that TB detection and treatment was an important migrant health issue.

Identified research gaps

The academic literature on TB in migrant populations along the Thailand-Myanmar border is relatively sparse. The literature shows that there are more TB and MDR-TB cases among non-Thais than among Thais in Tak province, Thailand and that treatment outcomes vary among groups (Hemhongsra et al., 2008; Minetti et al., 2010). In addition, TB surveillance, detection, and treatment among migrant groups have been identified as important issues (Ditton & Lehane, 2009; Hemhongsra et al., 2008; Kaji et al., 2015; World Vision Foundation of Thailand, 2012). The literature also demonstrates that community health workers and volunteers have been engaged by NGOs on both sides of the border to provide primary healthcare services (Back Pack Health Worker Team, 2015; International Organization for Migration & Ministry of Public Health, 2009; Lee et al., 2009; Sirilak et al., 2013).

Much remains unknown about TB, TB/HIV and MDR-TB in the refugee and migrant populations who access treatment in Tak province, Thailand. An identified gap is that the current literature does not address barriers to TB, TB/HIV and MDR-TB treatment as perceived by refugees, migrants, and service providers. A second gap in the literature relates to the responsiveness of healthcare providers and the PHSS to address the barriers refugees and migrants face in accessing TB treatment and entering the

surveillance system. A third identified gap is the role of community health volunteers in supporting TB surveillance and treatment in Tak province. While research shows that community health volunteers are active in the border region, further information on their surveillance and TB-related activities is necessary.

Part II: TB, HIV/AIDS, and MDR-TB

TB is re-emerging as a complex threat to human health. The disease's complexity lies amid its relationship with HIV/AIDS and the increased number of drug resistant cases that have emerged globally. In 2014 there were 1.1 million deaths worldwide from TB among HIV negative populations and an additional 0.4 million deaths associated with HIV (World Health Organization, 2015a). TB is a leading cause of death for people living with HIV/AIDS and a third of deaths among people living with HIV in 2014 were attributed to TB (World Health Organization, 2015a).

TB bacterium, *Mycobacterium tuberculosis*, is spread when an individual with active TB disease exhales. People who are exposed to TB bacterium do not always develop TB disease, although for some the bacteria can remain dormant in the body, a condition known as latent TB infection (Health Canada, 2012). Risk factors for latent TB infection include contact with someone suspected of having TB, living in a community with high rates of infection, and poverty (Health Canada, 2012). Latent TB can become active when the person's immune system is compromised and people with HIV/AIDS and diabetes have an increased risk of progressing from latent TB to active TB disease as compared to immune competent individuals (Health Canada, 2012).

Part III: TB, Social Determinants of Health and Migration

In the wider literature, beyond the Thailand-Myanmar border, the risk factors associated with active TB infection are closely linked to the social environments where people live.

TB risk factors

From the perspective of pathophysiology, tuberculosis is a very interesting disease. It is estimated that worldwide approximately one in every three people are infected with the TB bacterium (World Health Organization, 2015b). However the number of active TB cases, in which the disease causes damage, is much lower.

In examining the risk factors for TB it is important to consider both the risk of being infected with the bacterium and the risk of that infection becoming active TB. Narasimhan et al. (2013) explains that the risk of being exposed depends on one's environment whereas the risk that an exposure will lead to active TB is dependent on factors related to the individual. The risk of being infected with TB relates to the infectiousness (bacillary load) of an infectious case and one's proximity to this case (Narasimhan et al., 2013). The risk that such an exposure will lead to active TB depends on the individual and the susceptibility of his/her immune system. It has been widely documented that immune compromised individuals, such as HIV/AIDS patients, are much more susceptible to getting active TB if they are exposed to the TB bacterium. Narasimhan et al. classifies risk factors into the following groups: individual, socioeconomic and behavioural, demographic and ethnic and health system factors (2013). Individual risk factors include: immunosuppressive conditions, malnutrition, young age, diabetes, and being a health care worker (Narasimhan et al., 2013).

Socioeconomic and behavioural factors include smoking, alcohol consumption, and indoor pollution (Narasimhan et al., 2013). Demographic and ethnic factors highlight the high rates of TB that has been documented in indigenous and aboriginal populations (Narasimhan et al., 2013). These are linked to living conditions. Narasimhan et al. link health system challenges such as delays in accessing treatment for TB as a risk factor as delayed treatment lengthens the time an individual is infectious and thereby contributes to transmission (2013). Some of the risk factors for TB such as tobacco use are strongly associated with socio-economic status which has led to calls from epidemiologists to address TB from a multi-leveled approach which targets poverty (Millet et al., 2013).

From risk factors to social determinants of health

Tuberculosis is strongly linked to the social determinants of health. The World Health Organization defines the social determinants of health as, “the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life” (World Health Organization, 2016, np). Risk of tuberculosis exposure and subsequent progression to active TB is closely related to the places where people live and their socio-economic status. There is a socioeconomic gradient for TB between and within countries (Lönnroth, Jaramillo, Williams, Dye, & Raviglione, 2009; Narasimhan et al., 2013; Rasanathan, Sivasankara Kurup, Jaramillo, & Lonroth, 2011). TB status is inequitably distributed with higher numbers in disadvantaged populations. Many of the risk factors identified by Narasimhan (2013) are more concentrated in disadvantaged groups. For example, people in low socioeconomic status groups are more likely to live and work in crowded conditions with poor ventilation; are more likely to be

exposed to TB bacterium; are more food insecure; and have limited access to quality healthcare (Lönnroth et al., 2009). Lönnroth et al. (2009) make a differentiation between the proximate risk factors that increase exposure to TB bacterium and impair host defense and the upstream determinants such as the health system, poverty, migration, and economic policy. They created a framework to conceptualize proximate TB risk factors and upstream determinants.

The health system has been recognized as a social determinant of health (Commission on the Social Determinants of Health, 2008). Access to treatment for TB is important at both the individual and population levels. For individuals TB medical treatment is necessary and can be life-saving. Treating an individual with TB reduces that person's infectiousness to the surrounding community and also allows for active case finding to locate other TB cases.

Costs associated with accessing diagnosis and treatment for TB depend on the specific health system that is in place. In many countries out of pocket payment is required for these costs as well as indirect expenses (Rasanathan et al., 2011). High treatment expenditures are catastrophic and may lead to treatment default (Munro et al., 2007). Unfortunately defaulting on TB treatment may result in drug resistant TB which is clinically more difficult to treat and also much more expensive.

Historic data from England and Wales shows that TB mortality declined in the early 20th century long before TB drugs were available with slight increases in rates during the first and second world war (Lönnroth et al., 2009). Lönnroth et al. (2009) explain that this decline coincided with economic growth, social change, decrease in poverty, improved living standards, and medicinal and public health advances. However

the role of these factors in the decline of TB rates is still debated (Lönnroth et al., 2009). Rasanathan et al. (2011) and Lönnroth et al. (2009) argue that action on the social determinants of health is necessary for global TB control. Rasanathan et al. (2011) assert action on the upstream determinants such as poverty and intermediary determinants like HIV, malnutrition, smoking, alcohol, diabetes, and indoor air pollution could support future gains afforded through improved treatment and early diagnosis (Rasanathan et al., 2011). While national treatment providers can help to improve equitable access to treatment, many of the actions necessary to address poverty and other social determinants are outside of the scope of clinicians. Rasanathan et al. suggest intersectoral action as recommended by the World Health Organization 2011 report on the social determinants of health (2011). There are concerns that treatment interventions such as the implementation of Direct Observed Treatment (DOT) have not met their anticipated potential in reducing TB (Lönnroth et al., 2009). While TB has been declining, it has not been at the rate that was anticipated. Sluggish performance has been attributed by some to the social and economic determinants (Hargreaves et al., 2011; Rasanathan et al., 2011). Multiple authors have promoted action on the upstream social determinants as a means to fight TB (Hargreaves et al., 2011; Lönnroth et al., 2009; Narasimhan et al., 2013; Rasanathan et al., 2011).

TB and migration

Inequities in the distribution of TB are also linked to processes such as migration (Rasanathan et al., 2011). Those who migrate by irregular or clandestine means remain outside of the legal protections offered to legal migrants in the host country and also may

face health additional health risks during the migration process (Davies, Borland, Blake, & West, 2011). Careful consideration must be given to migrants' living conditions, their financial resources, and their ability to access the healthcare system in the host country. However it is also important to consider TB epidemiology and the migrants' conditions in their home country (Abarca Tomás et al., 2013). Abarca Thomas et al. (2013) conducted a systematic review of the qualitative literature on TB in migrant populations and suggest that, "Migrants' social, legal and economic circumstances can have a detrimental effect on TB's disease progression, it's diagnosis and treatment" (p.2). The systematic review identified the following barriers to accessing appropriate TB treatment for migrants: travel, difficulty understanding health information due to language barriers and impersonal tone, lack of awareness that free treatment was available, unavailability of treatment outside the migrants' working hours, and use of interpreters due to privacy concerns. Facilitating factors that assist migrants to adhere to TB treatment include: family support, advice from care providers and social contacts, and receiving care from those trained in TB or who have the ability to develop a personal relationship with the patient (Abarca Tomás et al., 2013). Absence of symptoms during treatment was identified as a barrier to adherence as patients feel better and do not see the need to continue taking their medication (Abarca Tomás et al., 2013).

TB Diagnosis

In reflecting on the context along the Thailand-Myanmar border it is useful to consider how TB is diagnosed. Figure 1 shows how TB is diagnosed by SMRU.

1. A **suspected TB patient** presents at the clinic.
2. A **sputum sample** is taken and the **Gene Xpert** test is used. A **chest x-ray** may be used at this time if they need to start treatment right away or are concerned about mobility. Using the chest x-ray they can look for lesions on the lungs.
3. The sputum sample is sent to the lab and a **sputum smear microscopy** is used in the lab to test for TB (3-4 days).
4. If the sputum smear or the Gene Xpert result are positive, they will send the sample to grow a **culture**. This takes 6-8 weeks. The culture will also be tested for drug susceptibility.

Figure 1. How TB is diagnosed among migrant and refugee patients at SMRU.

Theoretical Approach

This research project seeks to investigate healthcare accessibility from the perspective of patients and treatment providers with the specific objectives to understand how migrants and refugees access treatment and identify related barriers, enabling factors, healthcare responsiveness, and public health surveillance implications. As such, the project is primarily framed within a constructivist research approach in which reality is socially constructed and strongly linked to the local context. This research can be described as a qualitatively driven multi-methods project (Morse, 2003). Data was collected concurrently and this study has a smaller quantitative component, a community health volunteer survey, within the larger qualitative project. The purpose of using both qualitative and quantitative methods was to collect “two different pictures” of the situation (Creswell, 2009).

The theoretical approach that I have chosen for this project is informed by both the social determinants of health and the capability approach while remaining firmly rooted in theoretical discussions on access to healthcare. The literature suggests that TB and migrant health are related to the social, economic, and physical environments where people live. For this reason, I have incorporated the social determinants of health into the

project by seeking information on a wide range of barriers and enabling factors related to healthcare accessibility.

The capability approach, developed by Amartya Sen, has been applied to health (Anand, 2005; Prah Ruger, 2010). Health capability can be expressed as the ability or options people have to achieve health (Anand, 2005; Prah Ruger, 2010). It is important to note that “health” is subjective and the capabilities approach implies choice meaning that health capability refers more clearly to the ability to achieve a desired health status. In the access to healthcare model literature, the capability approach is integrated in reference to ability to receive care.

Social determinants of health models, such as the framework for risk factors and determinants of TB developed by Lönnroth et al. (2009), have strengths as explanatory tools that can help explain reasons for disparities in health outcomes. However, for this project I decided to use an access to healthcare model as it is action oriented and provides the opportunity to identify entry points for potential interventions to improve access to care. As this project is focused primarily on health care accessibility, I have selected a conceptual framework for access to healthcare that was developed by Levesque, Harris and Russell (2013) to use as a theoretical tool to guide the analysis of barriers and enabling factors. This framework builds on the work of access to healthcare theorists including Andersen (1995) and Pechanski & Thomas (1981). The strength of Levesque et al.’s 2013 model in the context of our project on access to healthcare for migrants is that it looks at both the healthcare system and the population. Levesque and colleagues (2013) conceptualize that access is related to both characteristics of the health care system and the ability of the patient population to interface with the system in order to gain care.

Levesque et al. (2013) utilize dimensions of health care system accessibility and population ability to further delineate factors that contribute to healthcare access. The five dimensions of accessibility are: 1) Approachability; 2) Acceptability; 3) Availability and accommodation; 4) Affordability; and 5) Appropriateness (Levesque, Harris, & Russell, 2013). Ability is divided into five parallel dimensions: 1) Ability to perceive; 2) Ability to seek; 3) Ability to reach; 4) Ability to pay; and 5) Ability to engage (Levesque et al., 2013). It is important to note that while Levesque et al. (2013) do not directly reference Sen’s (2009) capability approach, their emphasis on an individual’s ability to access to care is congruent with Sen’s conceptualization that capability is associated with freedom and an individual’s “actual ability” and “actual opportunity”(p. 253). Levesque et al.’s original model is presented in Figure 2 (Levesque et al., 2013). In article two I have further revised Levesque’s model based on our findings to make it more relevant to a mobile migrant population.

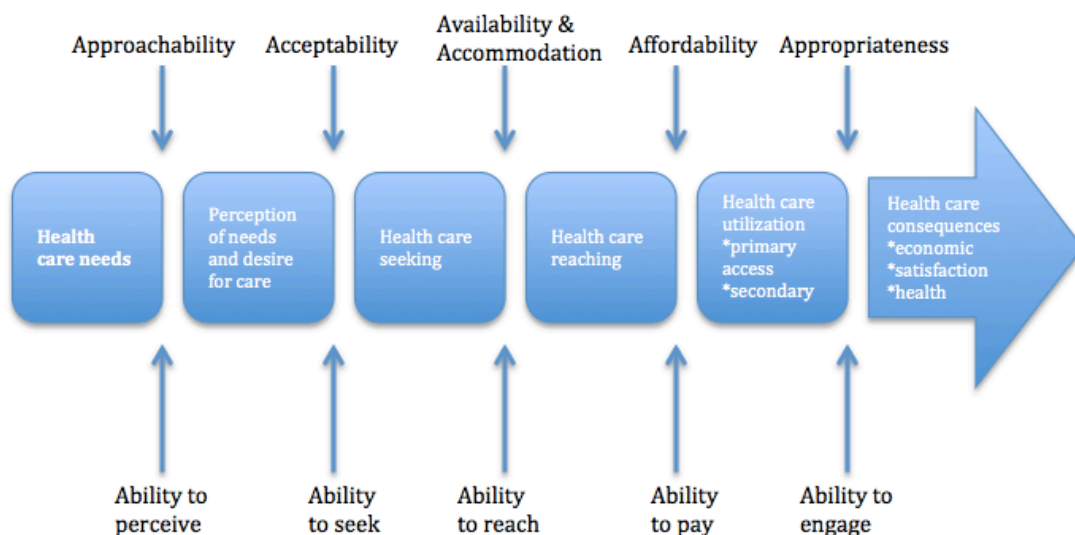


Figure 2. A conceptual framework of access to healthcare as developed by Levesque et al (2013).

Overview of the Thesis

I have employed a thesis by article structure. Following the introduction and research methods sections, I present four manuscripts that have been prepared for publication in peer-reviewed publications. Article 1 discusses TB and travel in the region and provides important context for the thesis. This manuscript has been published in PLOS One (Tschirhart, Sein, Nosten, & Foster, 2016a). Article 2 addresses access to TB treatment among migrants and refugees and was published in the International Journal for Equity in Health (Tschirhart, Nosten, & Foster, 2016b). Article 3 examines gaps and opportunities for TB control among migrant and refugee populations in Tak province and has been published in BMC Health Services Research (Tschirhart, Thi, Swe, Nosten, & Foster, 2017). Article 4 identifies how the health system has responded to the migrants' barriers to TB treatment. I have submitted the fourth article for consideration of publication in Health Policy and Planning. Following the articles, I conclude with a discussion section.

RESEARCH METHODS

Multi-Methods

Our decision to use multi-methods in this research project was guided by pragmatism and reflects Sale, Lohfeld and Brazil's (2002) view that qualitative and quantitative methods can be jointly used in a research project for the purpose of complementarity as "each method studies different phenomena" (p.50). Multi-methods allows the researchers to view a research topic from different angles, by using methods that are independently complete (Morse, 2003).

In deciding how to collect data, we considered which methods would help us to answer the research questions. We chose qualitative methods to examine TB treatment accessibility for migrants and refugees as well as the associated public health implications. However, at the time of the research proposal development the contribution of community health volunteers to TB treatment and surveillance was unknown and thus we decided to include a short quantitative survey to get baseline information about their participation.

We used the following methods to collect data: in-depth key informant interviews, focus group discussions (FGDs), participant observation, a survey, and a health service mapping exercise. I provide a brief description of each data collection method below:

Key informant interviews

I recruited key informants directly based on their professional role in infectious disease treatment and surveillance. I obtained contact information for potential key informants by contacting the health care organizations, through publicly available information or

through from my Co-Supervisor who has extensive contacts in Tak province. I recruited the KIs through email and telephone contact. We completed twelve key informant interviews between August and October 2014 and held one additional interview in December 2015. The purpose of these interviews was to gather information about TB, TB/HIV and MDR-TB treatment and surveillance based on participants' experiences as professionals working in the field. Interviews typically lasted one hour and were guided by a semi-structured interview guide.

Focus group discussions

Focus group recruitment varied slightly for patients and non-patient groups. The overall project was conducted in collaboration with researchers and clinicians at the Shoklo Malaria Research Unit. Patients were recruited from a TB treatment facility run by SMRU, a TB clinic at the Mae Sot hospital and through a refugee camp healthcare centre that is operated by Première Urgence - Aide Médicale Internationale (PU-AMI). Individuals who met the eligibility criteria were informed of the study by clinicians and clinic staff. Per standard research protocol, eligible individuals were told that participation is voluntary and that the decision to participate or not participate would not affect their rights to the medical care they normally receive. Clinic staff invited eligible individuals to come to the location of the focus group discussion at a pre-determined time.

Refugees who did not have TB were also recruited by staff at the TB village in the refugee camp who screened individuals for eligibility and invited them to come to come to the FGD location at a specific time. We had established the following eligibility for

criteria for this group: that they resided in a refugee camp in Tak province, were 20 years of age (legal majority) or older, were sufficiently fluent in spoken English, Burmese, or Karen to participate; did not have a confirmed or suspected case of tuberculosis; and were willing to provide consent to participate in the study. Given that the eligibility criteria were wide, we had some community health volunteers and partners of community health volunteers in the non-patient refugee group.

Migrants who did not have TB were the most challenging to recruit. We encountered difficulties recruiting non-patient participants as migrants often had heavy work responsibilities that made them unavailable to participate in research. In addition we found that it was difficult to recruit this population directly and that it was important to build a relationship with the local migrant community in efforts to build trust. In the end, we recruited non-patient migrants with the assistance of World Vision Foundation Thailand staff through their community health posts in Mae Sot district, Tak province. Staff informed community members of the research project, screened potential participants for eligibility and then scheduled a focus group and informed the participants of the time and date. Many of the participants were themselves also community health volunteers.

We held fifteen FGDs with a total of 92 refugees and migrants in Tak province. FGDs typically lasted between forty-five minutes to one hour and occurred in TB villages, a local hospital and two migrant communities in Mae Sot district. We chose the FGD method to investigate collective opinions about access to treatment and associated barriers or enabling factors. An additional benefit of the focus group method is that information exchange is iterative and one individual's contribution can prompt further

discussion from others. Kamberelis & Dimitraidis (2005) report that homogenous FGDs have been used in feminist research to create a safe space for discussion by organizing groups of individuals with similar backgrounds and experiences. Homogeneous group groups may be especially useful for focus group discussions on sensitive topics. Given the benefits of homogenous FGDs, we initially disaggregated participants into groups by three factors: gender, identification as a migrant or refugee and health status. Our rationale for disaggregating groups by these factors was that we anticipated that individuals in these sub groups would have different challenges accessing TB treatment. Health status was further divided into: TB patients, MDR-TB patients, TB/HIV patients and non-patients. The non-patient group was included with the aim of gaining insight into the perceived barriers for access to TB treatment among those who don't have TB.

As the research progressed we collapsed some of these subcategories out of necessity. For example, while the majority of focus groups were segregated by gender, two groups had both male and female participants. In another instance, refugees and migrants with MDR-TB were included in one group. I do not anticipated that this impacted the overall analysis as we found that mixed gender groups did not limit participation and I was able to disaggregate the contributions of migrants and refugees during the analysis.

When designing the research we made a conscious decision not to ask focus group participants about their legal status in Thailand in order to protect their privacy. However many participants self-identified and we had a considerable number of undocumented migrant participants.

Participant observation and community residence

The principal data collection for this research project took place over a three-month period from July to October, 2014. During this time I was a visiting doctoral researcher at the Shoklo Malaria Research Unit in Mae Sot and lived in the community. Prior to entering the field I had planned to use participant observation/community residence to observe how the PHSS functions. Once I arrived, I realized the logistical challenges associated with observing how data is recorded, transmitted and integrated across multiple organizations and instead focused on observing the work of TB doctors. I spent two days shadowing two different TB doctors and made notes. I also had the opportunity to visit and receive tours of several medical clinics and facilities. I used the information gathered from these observations to improve my contextual understanding of healthcare provision for migrants and refugees in the border region.

Survey of community health volunteers

We developed a short survey to examine the contribution of community health volunteers to TB, TB/HIV and MDR-TB treatment and surveillance. We approached organizations that support community health volunteers in Tak province to introduce our study and to ask if they would consider assisting with recruitment for the survey. It was originally anticipated that we would survey two groups of CHVs, those who are directly affiliated with a TB community mobilization program run by World Vision Thailand (WVT), and those who are not working directly in the domain of TB/HIV and TB. Once in the field, we decided that it was not feasible to collect data from the second group due to time and

resource restrictions. As such, the results from the survey may show how CHVs contribute to TB treatment and surveillance in the context of a TB program only.

We collected a total of 101 surveys in partnership with World Vision Foundation Thailand. I held a training session with World Vision staff on how to collect data and then the staff went out into the field and collected the information from the CHVs. Staff read the surveys to participants and wrote down the responses on paper forms.

Health service mapping

We used geographic information system (GIS) mapping during the analysis phase of this project to map the location of free or low-cost TB treatment for migrants and refugees in the border region of Tak province. I used data gathered through interviews, FGDs and observation to identify location of TB, TB/HIV and MDR-TB services and plotted these locations on a map using “my google maps” a free online software that allows users to customize their own map. We started with a map of Mae Sot and the surrounding study area and then input the locations of healthcare services using addresses or GIS coordinates, measurements of longitudes and latitudes, obtained from Google Earth maps. As health care access in the context of this research project is closely tied to legal status, colour coding was used to specify who can access treatment from each provider. I created separate maps to identify the types of services that were provided at each location. In June 2015 I returned the initial maps to Thailand for further discussion and refinement with project stakeholders.

While conducting the research it became evident that some migrants were traveling long distances to access treatment for TB. Participants in the MDR-TB patient

FGDs provided descriptions of their travel trajectory to access treatment at the clinic in Tak province, Thailand. Similarly to the health service mapping, I obtained GIS locations through Google Earth and then input them into our custom Google map.

Translation and Interpretation

We collected data for this research project in English, Thai, Burmese and Karen⁷. I initially developed all of the project materials in English and we subsequently translated the participant invitation letters, consent forms and survey. Once documents were translated, our project research assistant/interpreter Tabitha Sein verified the Burmese and Karen translations.

With the exception of key informant interviews that were conducted in English, the majority of data collection was completed with the assistance of one or two interpreters. Thai language interpreters assisted with interviews with Thai key informants and two research assistant/interpreters provided interpretation for the FGDs. Tabitha Sein interpreted from English to Karen and back from Karen to English and provided simultaneous summary interpretation from Burmese to English during the FGDs. Tabitha is a nurse with experience in qualitative health research. Kyaw Ye Min provided interpretation from English to Burmese. After each FGD together we debriefed and discussed the data. Prior to the data collection I held a qualitative research training session with both research assistants/interpreters. During the training, we conducted several practice FGDs followed by a debriefing session with a detailed discussion about key terminology.

⁷ Karen is a language spoken by the Karen ethnic group who are indigenous to the Thai-Myanmar border region. There are several dialects of Karen and our interpreter is fluent in Pwo Karen.

During data collection I recorded all of the interviews and FGDs. Subsequently I transcribed the English key informant interviews verbatim and the research assistants/interpreters transcribed the Thai, Burmese and Karen audio files directly into English.

Data analysis

Given the multi-methods nature of this project, we conducted data analysis separately for qualitative and quantitative data.

Qualitative analysis

During the data collection, I began to develop analytic memos about health care access as well as emergent themes (Miles et al., 2014). These memos helped me to identify potential ideas to further examine during the analysis. Much of our data consisted of narrative accounts of migrants' and refugees' own experience. As such these personal narratives offered what Williams & Elliot (2013) describe as "a broader interpretation that draws structure, context, behavior, and ill health into a single frame" (p.7). In developing an analytical plan to derive meaning from the key informant interviews and focus group discussions, I selected content and thematic analysis for its flexible nature ability to narrow the focus of the inquiry while being open to emerging trends in the data. Thus my approach to thematic analysis was both deductive and inductive in nature (Pope, Ziebland, & Mays, 2000). I developed deductive or *a priori* thematic codes based on the interview guides and created an associated coding scheme. Strategically, to keep the analysis close to the data I also employed inductive codes, which I identified in the data during the analysis. I analyzed the data using NVivo qualitative software version 11 for

mac. I uploaded the transcripts into NVivo and then subsequently coded them. I organized codes into sub categories and categories during the analysis and identified themes, essentially ideas or patterns that I identified as pertinent to the overarching research question (Braun & Clarke, 2006; Guest, MacQueen, & Namey, 2012). This iterative process began during initial coding and continued until the end of the analysis with movement between the codes, themes and raw data, until clear themes emerged which answered our project's research questions (Braun & Clarke, 2006). As an extension of the thematic analysis, I took the codes associated with barriers and enablers for healthcare access and created visual representations or thematic maps on paper specific to migrant and refugee respondents (Braun & Clarke, 2006). I then took the barriers and enabling factors and plotted them onto Levesque et al.'s (2013) conceptual framework for healthcare access, and subsequently created a revised model that I brought back to Thailand to discuss with stakeholders.

During the analysis it became evident that migrants were travelling long distances to obtain TB treatment and I perceived that it would be valuable to document the individual trajectories. With this in mind, I reviewed the transcripts and constructed a table in Excel version 14 to identify the individual trajectories of migrants and refugees.

Quantitative analysis

I manually entered the survey data into an excel file, which I then imported into IBM SPSS Statistics version 24 for analysis. SPSS is a statistical analysis software program. Given that we have a non-randomized sample our analysis is limited to descriptive statistics (Healey & Prus, Steven, 2015).

Research Ethics

Participants provided verbal consent prior to participating and during the consent process the interpreter explained that they were free to withdraw or not answer questions without consequence. We also explained that participation would not impact or enhance patient's access to the healthcare that they typically receive.

We ensured interview and survey participants' privacy and confidentiality by masking/redacting personally identifying information in the transcripts. Due to the nature of focus groups it was not possible to guarantee privacy and confidentiality among participants. However at the beginning of the session, we asked participants to maintain confidentiality and explained that it could not be guaranteed. Our research assistant/interpreters also signed a confidentiality agreement. All names that are used in the articles within the thesis are pseudonyms.

Copies of the ethics approvals we received from the Health Sciences and Sciences Research Ethics Board at the University of Ottawa (File #H02-14-08), the Oxford Tropical Research Committee at the University of Oxford (538-14) and the Tak Provincial Public Health Office (TK 1/2557) are included in the appendices.

Article 1. Migrant and Refugee Patient Perspectives on Travel and Tuberculosis along the Thailand-Myanmar border: A Qualitative Study

Naomi Tschirhart, Tabitha Sein, Francois Nosten, Angel M. Foster

Author Note

Naomi Tschirhart, Faculty of Health Sciences, University of Ottawa, Shoklo Malaria Research Unit, Mahidol-Oxford Tropical Medicine Research Unit, Faculty of Tropical Medicine, Mahidol University; Tabitha Sein, Shoklo Malaria Research Unit, Mahidol-Oxford Tropical Medicine Research Unit, Faculty of Tropical Medicine, Mahidol University; Francois Nosten, Shoklo Malaria Research Unit, Mahidol-Oxford Tropical Medicine Research Unit, Faculty of Tropical Medicine, Mahidol University, Centre for Tropical Medicine and Global Health, Nuffield Department of Clinical Medicine, University of Oxford; Angel M. Foster, Faculty of Health Sciences, University of Ottawa.

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Abstract

Background

The Thailand-Myanmar border separates two very different health systems. The healthcare system in eastern Myanmar remains underdeveloped as a result of decades of instability. Comparatively, Tak province, Thailand has more healthcare resources. In this Thai border province government hospitals and non-governmental organizations provide tuberculosis (TB) treatment to migrants and refugees.

Objectives

Our overall study aimed to explore accessibility of TB treatment, TB surveillance and health system responsiveness specific to migrant and refugee populations in Tak province. In this paper, we focus on the perspectives of migrant and refugee TB patients with respect to travel and treatment in Tak province.

Methods

In 2014 we conducted focus group discussions with 61 TB, Tuberculosis and Human Immunodeficiency Virus co-infection, and multidrug-resistant TB patients in Tak province. We analyzed the data for content and themes and documented individual travel trajectories.

Results and Discussion

Migrants are travelling with active TB within the country and between Thailand and Myanmar. Migrants primarily travelled to obtain treatment but two participants reported travelling home to seek family care in Myanmar before returning to Thailand for treatment. Travel, while expensive and arduous, is an adaptive strategy that migrants use to access healthcare.

Conclusions

Migrant's need for travel points to larger difficulties associated with healthcare access in the border region. Long distance travel with an infectious disease can be seen as an indicator that local healthcare is not available or affordable. These findings suggest that public health officials from both sides of the border should discuss the factors that contribute to travel with active TB and explore potential solutions to mitigate disease transmission in migrant populations.

Keywords: Myanmar; Tuberculosis; Drug Resistance; Refugees; Migrants; Travel; Migration; Public Health; Population Health

Introduction

Tak province is situated in northwestern Thailand and borders Kayin state, Myanmar. The Thailand-Myanmar border separates two very different health systems. The healthcare system in Kayin state and other regions of eastern Myanmar remains underdeveloped as a result of decades of instability and lack of investment in public health infrastructure. In eastern Myanmar healthcare is primarily provided by community-based health organizations and for many people in this region government facilities are unavailable or inaccessible (Health Information Systems Working Group., 2015). Comparatively, Tak province has more healthcare resources including a greater number of clinics, hospitals, and health professionals. Tak province can be described as a middle resource setting as compared to a high resource setting like Bangkok that has more specialist hospitals. In Tak province there are five district government hospitals as well as three organizations, Première Urgence - Aide Médicale Internationale (PU-AMI), the Shoklo Malaria Research Unit (SMRU), and the International Organization for Migration (IOM), that provide TB treatment to migrants and refugees. The Thailand-Myanmar border in Tak province is known for its fluidity. The border in Tak province is 500 kilometers in length and the two countries are separated by the Moei River. Migrants can easily swim or take a boat to cross the river. It is not unusual for individuals living in Myanmar to cross over the Thai border to receive treatment at one of the clinics that is dedicated to providing health services for migrants. For this project migrant is defined as an individual who has resided in a foreign country for more than one month or who has crossed a national border to access essential services, irrespective of the causes, voluntary or involuntary and the means, regular or irregular used to migrate. Individuals who have

received refugee status are not considered migrants. This description is adapted and modified from a definition used by the International Organization for Migration.

Myanmar and Thailand are both countries with a high burden of people living with tuberculosis (TB), however the prevalence is significantly higher in Myanmar (473/100,000) than in Thailand (149/100,000) (World Health Organization, 2014a). Myanmar is also more heavily burdened with multidrug-resistant tuberculosis (MDR-TB) and it is estimated that 5% of new TB cases and 27% of retreatment cases are multi-drug resistant (World Health Organization, 2014a). Comparatively, in Thailand it is estimated that 2% of new and 19% of retreatment cases are MDR-TB (World Health Organization, 2014a). Tuberculosis has been identified as an important public health issue in Tak province by the Tak provincial public health office (Iemrod & Kavinum, 2015). A review of provincial surveillance data for 2006-2011 showed that the majority of TB patients were in Mae Sot district most of whom were non-Thais (Iemrod & Kavinum, 2015). Mae Sot is largest urban center along the Thailand-Myanmar border and has been rapidly changing from a small border town to a large special economic zone. A 2007 pilot study also found that the burden of TB in Tak province is higher among migrant populations as 65% of TB patients were non-Thais (Hemhongsra et al., 2008).

In Tak province treatment for TB is provided by both government hospitals and non-governmental organizations (NGOs). Migrants can register and pay into Thailand's Compulsory Migrant Health Insurance scheme which is a form of insurance providing coverage for healthcare at Thai government hospitals inclusive of TB treatment. Non-Thais without insurance can pay out of pocket for services at the government hospitals but most low waged migrants cannot afford the treatment fees. TB treatment at the Mae

Sot Hospital is non-residential and at the time of our study World Vision Thailand was providing Directly Observed Treatment (DOT) to migrants living in urban Mae Sot, Thailand. DOT was not provided to migrant TB patients who were living in Myanmar and crossing the border to get treatment at the Thai government hospital. In Tak province PU-AMI and SMRU have set up residential TB treatment programs specifically for migrants and refugees who are not eligible to receive low cost treatment from Thai government hospitals. PU-AMI provides TB and Tuberculosis and Human Immunodeficiency Virus co-infection (TB/HIV) treatment in the refugee camps. SMRU treats migrants and refugees with TB, TB/HIV and is the only NGO in Tak province that provides MDR-TB treatment to this population. Both PU-AMI and SMRU have residential TB villages where patients can stay during treatment and receive daily DOT. The TB villages are overseen by TB doctors and are staffed by medics who are migrants and refugees from Myanmar. IOM gives TB treatment specifically to refugees who are relocating to a third country. There are linkages between the treatment providers and in 2012 SMRU, PU-AMI, IOM and the Tak provincial public health office, created the Tak Tuberculosis Initiative (TTBI) as a mechanism to collaboratively address the TB burden in Tak province (Shoklo Malaria Research Unit, 2014). The five district hospitals are TTBI implementing partners and received funding to provide TB treatment for migrants through a grant from the United Kingdom's Department for International Development and the European Union. World Vision Thailand does not provide clinical treatment for TB but plays an important role by helping to refer symptomatic patients and providing supportive care and DOT for migrant patients who were treated at the Thai government hospital.

Methods

Our interdisciplinary team conducted substantive data collection in the summer and fall of 2014 with an additional data collection period in December 2015. In brief our overall study included key informant interviews with treatment providers and public health officials (n=13), 15 focus group discussions (FGD) with TB patients (n=61) and non-patients (n=31), and a survey of community health volunteers (n=101). We designed this multi-method research project to explore access to TB treatment among refugee and migrant populations in Tak province. Our primary research objective for the overarching research project was to identify how migrants and refugees access TB, TB/HIV and MDR-TB treatment in Tak province. During the initial analysis we found that migrants are travelling long distances within Thailand and across the border to and from Myanmar with active TB. In this paper we focus on the perspectives and experiences of migrant and refugee patients with respect to travel and treatment.

Data collection: focus group discussions

We held FGD with migrants and refugees who were living or seeking healthcare in Tak province. To create a safe space for discussion we attempted to create homogenous focus groups with participants disaggregated by health status, gender, and migrant or refugee identification (Kamberelis & Dimitraidis, 2005). We prioritized holding different FGD based on health status as we anticipated participants would have specific challenges related to differential availability of TB, TB/HIV and MDR-TB care in Tak province. We conducted eleven FGDs for TB, MDR-TB, and TB/HIV patients and four FGD with non-patients. As treatment providers often provided care to both migrant

and refugees, some FGD had both refugees and migrants. We do not anticipate that this affects the study as participants gave their personal histories and we used this information to differentiate between refugees and migrants. In total, sixty-one patients with TB, TB/HIV or MDR-TB participated in the FGDs. Our research participants had diverse backgrounds including migrant workers who were living in Thailand, migrants who had travelled from Myanmar for treatment, and residents living in a camp along the border. We present participant information in Table 1. While our non-patient migrant FGD participants indicated that they had challenges to access healthcare generally, we have not included their data in this particular article as they did not travel with TB. These migrants who were living in Mae Sot, Thailand indicated that they had challenges accessing healthcare related to their legal status, however they had less difficulty than migrants who had travelled from Myanmar or other provinces as free healthcare is readily available for migrants in Mae Sot at the Mae Tao Clinic.

Table 1.1 Composition of TB Patient Focus Groups

FGD	Location	Type	Participants	Description
1	Mae La TB village	Men with TB	6	Refugees and Migrants
2	Mae La TB village	A man and woman with active TB	2	Refugees
3	Mae La TB village	Women with TB	5	Refugees and migrants
4	SMRU TB village	Women with TB	5	Migrants
5	SMRU TB village	Men with TB	7	Migrants
6	SMRU TB village	Women with TB/HIV	7	Migrants
7	SMRU TB village	Men with TB/HIV	8	Migrants
8	SMRU TB village	Women with MDRTB	6	Refugees and migrants
9	SMRU TB village	Men with MDRTB	7	Refugee and migrants
10	Mae Sot Hospital	Women with TB	3	Migrants
11	Mae Sot Hospital	Women and Men with TB	5	Migrants

We recruited patients from a TB treatment facility run by SMRU, a TB clinic at the Mae Sot Hospital, and through a refugee camp healthcare centre that is operated by Première Urgence-Aide Médicale Internationale. Clinicians and clinic staff informed eligible individuals of the study, explained that participation is voluntary and clarified that the decision to participate would not affect their right to receive medical care. Prospective participants who indicated that they were interested were informed of the location and time of the FGD. As this is a highly mobile population residing in a large geographic area spanning two countries, we know from previous experience that it is beneficial to have the FGD shortly after the recruitment period. In the case of this research project, we conducted the focus groups within one to two days of recruitment.

We held the FGDs at the Mae Sot Hospital, the Mae La refugee camp TB village, the SMRU TB village, and at two community health posts in Mae Sot. Each place where we held a discussion was quiet, secure and separate from where clinical and counseling services were provided. Participants received 150 baht (approximately USD 4) as a reimbursement for travel expenses as well as food to take home. All participants consented for the FGDs to be audio recorded. After obtaining consent, NT conducted the focus groups with the assistance of a Burmese-speaking interpreter and TS, a co-facilitator and Karen-speaking interpreter. Focus group discussions lasted approximately 45 minutes and explored participants' pathway to treatment as well as the resources that enabled them to continue treatment.

Data Analysis

TS transcribed the Karen and Burmese audio recordings into English. We then analyzed the transcripts and coded the data in Nvivo using *a priori* (predetermined) and emergent codes. NT then conducted second and third level analysis to categorize content and identify themes. During the analysis we identified travel with TB as an emergent theme, which we explore in detail in this paper. With the aim of further investigating travel, NT went back to the raw data and documented the individual journeys by identifying the geographical locations that participants described visiting during their quest for TB treatment. Where trajectory information was unavailable we still included any travel related contributions in the thematic analysis. We also used Google My Maps to calculate approximate distances that the patients travelled to gain access to treatment and to map travel trajectories. We returned to Mae Sot in Tak province in June 2015 to

present our preliminary findings to stakeholders many of whom participated in the research as key informants. These presentations and the subsequent discussions served as a member checking exercise that allowed us to enhance the quality and “trustworthiness” of our findings (Guba & Lincoln, 1994). In this paper we have organized the results by theme.

Ethics

We received research approval for this study from the Health Sciences and Sciences Research Ethics Board at the University of Ottawa (File #H02-14-08), the Oxford Tropical Research Ethics Committee at the University of Oxford (538-14) and the Tak Provincial Public Health Office (TK 1/2557). To protect the identity of the participants we have masked all personally identifying data and have used pseudonyms. Pseudonyms are commonly used in qualitative research to mask the identity of the participant.

Results

We collected partial or full travel trajectory information from forty-two migrant patients. Some of the migrant patients were living in Tak province, while others resided in Myanmar or Bangkok and had travelled to get treatment. Trajectory information was missing for eleven migrant patients and we did not collect it from eight refugees. Comparative to the migrant population in this study, refugees were less mobile and were living inside a gated refugee camp. As TB treatment is available inside the refugee camp where we conducted the FGDs, most refugee patients did not need to travel outside of the

camp boundaries to get treatment. For refugee patients with MDR-TB, the health care provider PU-AMI organized free transportation outside the camp to the SMRU clinic. Refugee participants did not embark on independent travel with TB and reported limited challenges accessing treatment. In the results section we explore the experiences of migrant patients.

Migrants are travelling with active TB

During several FGDs participants from Myanmar described travelling with symptoms of active tuberculosis. In some cases individuals knew or suspected that they had TB based on a past clinical TB diagnosis. Of the forty-two patients that travelled it is likely that most were infectious as all of them had TB that was either untreated or not responding to treatment. The exception is one patient who had bone TB which is not infectious. Our FGD participants shared their own stories of travel. Their journeys began in locations with varying levels of healthcare resources and ended with TB treatment in Tak province. Some travelled from higher healthcare resource settings like Bangkok and others came from villages in rural Myanmar with low healthcare resources. Migrants' travel to TB providers in Tak province originated within the province (n=15), from Myanmar (n=21), and from Bangkok (n=2). In addition four patients crossed the Thailand-Myanmar border twice by travelling from Bangkok, Thailand to Myanmar and then back to Tak province. FGD participants used their social networks to locate and gain access to TB treatment. Patients and their family members asked neighbors, friends and healthcare workers where they could get treatment. In one case a woman in Thaton, Myanmar met two monks who were travelling to Thailand to get healthcare and asked

permission to follow them. Several participants came to stay with their family member in the refugee camp in order to access health services.

Migrants primarily travelled to access TB treatment

I am from Rangoon [Yangon], I came here just to get treatment. I arrived in Thailand over a year ago and spent 2 months in Mae La [Refugee] Camp. I have been taking MDR-TB medication for 13 months now. I received TB treatment at Rangoon for only one month and I was not feeling better. They asked me to stay at the hospital and tested my sputum for bacteria so many times. Then they found out that I had MDR-TB. The medication for MDR-TB was very limited so I had to wait for the new medication to come. Myat Noe, female migrant MDR-TB patient.

Most FGD participants travelled exclusively to get treatment. Participants came from Myawaddy and Koko which are directly across the border from Tak province as well as further inside Myanmar including Yangon (440 km) and Mawlamyine (180 km) specifically to seek TB care. Participants who were living in Thailand, both Bangkok (500km) and Tak province, also travelled primarily to get TB treatment for themselves. The two exceptions were patients who initially arrived at a TB clinic in Tak province in the role of a support person accompanying a TB patient. In this case the individuals undertook travel to get treatment for their loved one not realizing that they also had TB.

Participants described travel as expensive and arduous and explained that they needed to travel because they could not get appropriate and effective care locally. Treatment failure, treatment unavailability and treatment unaffordability influenced

participants' decisions to travel. Referrals from individuals who had heard of free health services available in Tak province also factored into the decision to travel.

FGD participants who had received unsuccessful TB treatment explained that they were not getting better and subsequently decided to travel to seek care. Reports of previous treatment failure were more common among patients with MDR-TB than drug susceptible TB or TB/HIV. Some of the MDR-TB patients described knowing that they had drug resistant TB while others only knew that they were unwell and that previous treatment didn't work.

Here we explore the trajectory of one MDR-TB patient. Figure 1.1 traces the 1214 kilometer travel trajectory of Saw Paul, a Karen man from the original location where he sought treatment to the SMRU TB in Tak province village where he received treatment for MDR-TB approximately two years later. In 2011 he travelled from Kaw Ler village to Hpa-An which is a mid-sized town in south-eastern Myanmar to receive his first seven month treatment. Unfortunately it was not effective and he got a second seven month course of medication in Hpa-An. After two rounds of unsuccessful treatment he went with his daughter to Bangkok (654 km) and purchased TB medication from a pharmacy and treated himself for nine months. Saw Paul still didn't feel better so he travelled 560km north to the Mae La refugee camp where he received treatment before being referred to the nearby SMRU TB village (61 km) for MDR-TB treatment.



Figure 1.1: MDR-TB patient's travel trajectory from Hpa An, Myanmar to seek TB treatment in Tak province. Lines indicate travel pattern. Image similar but not identical to original created using the USGS National Map Viewer and therefore used for illustrative purposes only.

Where treatment was available, some participants who were living in Myanmar and Bangkok when they fell ill explained that they could not afford to seek treatment locally due to high treatment costs. A second reason that participants travelled to get treatment is that the treatment that was available closest to them was unaffordable. Patients who were living inside Myanmar and those who were working in Bangkok when they fell ill explained that they could not afford to seek treatment locally due to high treatment costs. Myanmar has a national health care system where costs are shared

between the patient and the government. In Bangkok, migrants who have not registered and paid to join the government health insurance scheme must pay out of pocket for health services.

In searching for a place to get treatment patients relied on advice from friends and family members. Mae Tao Clinic (MTC), a well known clinic in Tak province that provides health services to migrants, was identified as a preferred treatment centre. MTC tests symptomatic patients for TB and refers clients to another provider in Tak province for TB treatment. While most FGD participants initiated their own travel plans after consulting with friends and family, three patients were referred from outside Tak province. A physician in Bangkok told one patient to travel to MTC for treatment, a second patient was referred to Mae Sot hospital from Myawaddy Hospital for bone TB treatment due to insufficient medication and medical equipment and a third patient with MDR-TB was referred from an IOM clinic in Mawlamyine, Mon State, Myanmar.

The need for family support can motivate travel with TB

While most of the FGD participants travelled with TB exclusively to seek treatment, four patients took a circuitous route which involved travel home to Myanmar from Thailand before returning to Thailand for treatment. Two of the participants described why they took this route. Both women were working in Bangkok when they fell ill with TB and subsequently decided to go home to Myanmar so their families could take care of them. One woman didn't have the legal documentation required to obtain low cost healthcare at Thai government hospitals and the second had the required insurance but didn't want to burden her husband with the responsibility to take care of

her during a second course of TB treatment. Both women described that when they returned to Myanmar they found that treatment was unavailable close to their family home and that travel and treatment costs were unaffordable. They subsequently decided to return to Tak province for TB treatment.

Travel for migrants is arduous

Of course I have no money and so I walk to die even though I have no energy.

Aung, male TB patient.

FGD research participants described arriving at the clinic by different means of transportation. Some walked but most took shared transportation such as cars or buses. Patients who were referred from clinics within Tak province received free transportation from the health service provider. Travel can be expensive and travel costs were identified as a barrier to accessing treatment. Some participants borrowed money to be able to make the trip. For migrants without proper documentation travel can be logistically challenging and significantly more expensive. Undocumented migrants described paying higher rates to take routes to avoid the police. Many participants expressed fear of being stopped by the police and being asked to pay a lump sum or face deportation. In selecting where to get treatment migrants described making comparative calculations of the total costs inclusive of treatment and transportation fees. Eka a migrant woman from nearby Myawaddy which is directly across the border articulated the comparative financial implications, “we have to pay for the transportation fees only, not the treatment fees so we choose to come here. In Burma we have to pay both”. For patients like Eka in

Myawaddy it is closer to travel to Mae Sot in Tak province Thailand (less than 10km) than further inland to Mawlamyine (172km).

Discussion

Cross border travel for the purpose of seeking healthcare along the Thailand-Myanmar border has been well documented in the literature (Hemhongsra et al., 2008). However less is known about the rationale for travel from the patient perspective. Our study contributes new knowledge to this area. We found that migrants are travelling long distances with symptoms of active TB to seek medical treatment or to return home to receive care from their family while they are ill.

Travel is an adaptive strategy used to access TB treatment

Migrants described travel as expensive and arduous. Yet despite the associated difficulties including police bribes and the risk of deportation, travel was often deemed necessary. Our findings suggest that the need to travel emerges from contextual factors that shape the environment where migrants live and work. Specifically along the Thailand-Myanmar border the decision to travel is influenced by synergistic interactions between different social determinants of health including migration, the healthcare system and material circumstances. Our research supports the notion that migration itself is a social determinant of health given the social inequalities migrants face and the health impacts of the migration process (Davies, Basten, & Frattini, 2006). We found that migrants' legal status and personal finances influenced where they are eligible to receive healthcare. For example several patients travelled to the capital of Thailand, which has

extensive health care services, then to Tak province as they were not eligible to receive free or low cost care in the capital Bangkok because they were not registered in the Thai government's migrant health insurance scheme. Unaffordability of health services in Myanmar also contributed to patient's decisions to travel to Tak province where they could receive free or low cost treatment. Our results suggest that availability of care is an important consideration. Where care is not available locally travel becomes necessary. This theme was especially prominent for MDR-TB patients who often travelled to several locations to seek treatment before coming to Tak province. We expect that the continual search and the associated extensive travel were financially catastrophic for patients. Daily waged migrants who participated in this research described travel costs that often exceeded their daily wage even for those that were travelling shorter distances from within Tak province. From a population health perspective, travel can be seen as an adaptive strategy for migrants who are seeking to gain access to TB treatment. We observe that migrants' decision to travel is linked to the high individual and familial costs associated with TB in their specific context. For example, migrants living in locations where free TB treatment was not available indicated concerns about treatment costs in addition to lost wages. Migrants described weighing the decision to travel and comparing it against their other options. In using their social networks to find out where they can get treatment they demonstrate resiliency and resourcefulness. Finally the existence of TB treatment provided by NGOs in Tak province allows migrants the possibility to access free treatment through travel. Our research supports the notion that migrants will continue to come to access healthcare in Tak province until healthcare accessibility improves in Myanmar (Hemhongsra et al., 2008).

Going home with TB

In conducting this research we did not expect to find four cases of migrants who travelled with TB from Bangkok, Thailand to Myanmar. This finding is particularly surprising in the case of one woman who had health insurance and could access healthcare in Thailand's capital city for a nominal fee but chose to return to Myanmar so that her family could take care of her during her illness. Given that only two participants indicated that they were travelling home specifically to be with their family, these cases serve as an anomaly, albeit an important one. Our limited data suggests that social support and care is important during treatment and compliment the findings of a study from India that documented migrants moving back to their home village following TB illness (Jayachandran, 2014). Further research may be necessary to explore TB treatment, social support and decisions to return home among patients from Myanmar. Additional insight into the decision to travel while ill from a high healthcare resource setting to a low resource setting may be especially valuable. We anticipate that these decisions are likely multi-dimensional and may take into account social support as well as treatment and living costs.

Public health implications

Patients who participated in our project did not articulate concerns about TB transmission during travel, however travel with active tuberculosis on public transport has broader health implications. In our study we identified forty-one patients who travelled with TB that was untreated or not responding to treatment. People with active TB who are travelling short or long distances on shared public transportation can

potentially expose other passengers to TB bacteria. People travelling across borders with MDR-TB is even more concerning as MDR-TB is more difficult and expensive to treat than drug susceptible TB. Additionally, inadequately treated MDR-TB in individuals with HIV has been shown to be highly infectious (Escombe et al., 2008). In this study migrants described travelling by shared car, bus and boat to reach health services in Tak province. Given the small number of studies conducted of TB transmission on public transport, it is difficult to quantify the risk and to define the public health implications (Mohr et al., 2012). However, other work suggests transmission is possible and in a study from Spain a single six hour bus ride with one TB case led to a transmission rate of 21/53 (39.6%) and five contacts subsequently developed active disease (Mohr et al., 2012). Crowding, duration and cumulative exposure increase the risk of TB transmission (Mohr et al., 2012).

In high TB burden contexts like Thailand and Myanmar it is possible that an individual patient was exposed to TB bacteria multiple times prior to the disease. Multiple exposures, a long incubation period and the challenge of tracing cases across national borders make it is difficult to attribute TB disease to one specific ride on public transport. Our data suggests migrants with TB may undertake multiple trips in order to get effective treatment. Migrants experienced delays in accessing treatment due to availability and affordability of care. Delayed TB diagnosis is common among migrants (Abarca Tomás et al., 2013). Treatment delays extend the length of time the individual is infectious and contribute to transmission (Narasimhan et al., 2013). Delayed treatment further perpetuates the cycle of TB infection and disease among the migrant community. Lack of accessible and appropriate TB care may also contribute to patient's decisions to

self manage their own TB regimens. While only one participant in our study purchased their TB medication from a pharmacy, self-treatment is an urgent threat for drug resistance and is an important public health concern in this region.

Limitations

One of the limitations that we identified is that this research project only collected information from individuals who successfully accessed treatment. We know much less about individuals with TB who have not been able to get treatment. An additional limitation is the temporal nature of the study. Our team conducted the FGDs in September and October 2014. Access to healthcare for migrants continues to evolve as policies change. As such our results should be interpreted with reference to the specific temporal period. While we conducted our recruitment with the assistance of clinicians and clinic staff at TB facilities, participants were informed that their participation was voluntary and we do not anticipate that this has any implications for our findings. The results from this qualitative research project are not generalizable to all migrants and refugees on the Thailand-Myanmar border. However, we hope our findings on rationale for travel may probe additional research along the border and in other regions.

Conclusions

For migrants, traveling long distances is costly and logistically challenging. In choosing to travel individuals have often exhausted other options for getting medical treatment and supportive care. Migrants explained that they travelled with active TB either to get treatment or to return home to their family. Travelling with active TB on public transport

has an inherent risk for TB transmission, however we identified travel as an adaptive strategy that migrants use to gain access to healthcare. Our finding that cost and unavailability of TB and MDR-TB treatment contribute to mobility across provincial and national boundaries has important implications for public health officials in the region. The results point to larger difficulties associated with healthcare access. Long distance travel with an infectious disease can be seen as an indicator that local healthcare is not available or affordable. Public health officials from both sides of the border could discuss the factors that contribute to travel with active TB and explore potential solutions to mitigate disease transmission in migrant populations.

Article 2. Access to free or low-cost Tuberculosis treatment for migrants and refugees
along the Thailand-Myanmar border in Tak province, Thailand

Naomi Tschirhart, Francois Nosten and Angel M. Foster

Author Note

Naomi Tschirhart, Faculty of Health Sciences, University of Ottawa, Shoklo Malaria Research Unit, Mahidol-Oxford Tropical Medicine Research Unit, Faculty of Tropical Medicine, Mahidol University; Francois Nosten, Shoklo Malaria Research Unit, Mahidol-Oxford Tropical Medicine Research Unit, Faculty of Tropical Medicine, Mahidol University, Centre for Tropical Medicine and Global Health, Nuffield Department of Clinical Medicine, University of Oxford; Angel M. Foster, Faculty of Health Sciences, University of Ottawa.

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Abstract

Introduction

In Tak province, Thailand migrants and refugees from Myanmar navigate a pluralistic healthcare system to seek Tuberculosis (TB) care from a variety of government and non-governmental providers. This multi-methods qualitative study examined access to TB, TB/HIV and multidrug-resistant tuberculosis (MDR-TB) treatment with an emphasis on barriers to care and enabling factors.

Methods

In the summer and fall of 2014, we conducted 12 key informant interviews with public health officials and TB treatment providers. We also conducted 11 focus group discussions with migrants and refugees who were receiving TB, TB/HIV and MDR-TB treatment in Tak province as well as non-TB patients. We analyzed these data through thematic analysis using both predetermined and emergent codes. As a second step in the qualitative analysis, we explored the barriers and enabling factors separately for migrants and refugees.

Results

We found that refugees face fewer barriers to accessing TB treatment than migrants. For both migrants and refugees, legal status plays an important intermediary role in influencing the population's ability to access care and eligibility for treatment. Our results suggest that there is a large geographical catchment area for migrants who seek TB treatment in Tak province that extends beyond provincial boundaries. Migrant participants described their ability to seek care as linked to the financial and non-financial resources required to travel and undergo treatment. Patients identified language of health

services, availability of free or low cost services, and psychosocial support as important health system characteristics that affect accessibility.

Conclusion

Access to TB treatment for migrants and refugees occurs at the interface of health system accessibility, population ability and legal status. In Tak province, migrant patients draw upon their social networks and financial resources to navigate a pathway to treatment. We revised a conceptual framework for access to healthcare to incorporate legal status and the cyclical pathways through which migrants access TB treatment in this region. We recommend that organizations continue to collaborate to provide supportive services that help migrants to access and continue TB treatment.

Introduction

Tak province in northwestern Thailand shares an international border with Kayin (Karen) State, Myanmar. The Moei river, a narrow body of water, demarcates the border between these two countries. While the official border crossing between Mae Sot, Thailand and Myawaddy, Myanmar has a bridge, many cross the river unofficially at other locations using small boats. The border area of Tak province and Kayin state are both mountainous regions characterized by rolling hills, dusty roads, heavily forested areas and rice fields. The population of Tak province includes approximately half a million Thai citizens, 90,000 refugees, 300,000 registered migrants and an unknown number of unregistered migrants (Iemrod & Kavinum, 2015). In addition to the migrant population that is living and working in the province there is significant cross-border travel among individuals who live in Myanmar but come to Thailand temporarily to access essential services, including healthcare (Hemhongsra et al., 2008). In Tak province, five district government hospitals as well as *Première Urgence - Aide Médicale Internationale* (PU-AMI), the Shoklo Malaria Research Unit (SMRU), and the International Organization for Migration (IOM) deliver tuberculosis (TB) treatment to refugees and migrants from nearby Myanmar. IOM also treats TB patients on the Myanmar side of the border along with the Myanmar National TB Programme.

Previous research found a higher incidence of TB among refugees and migrants than Thai citizens living in Tak province (Hemhongsra et al., 2008). Recent figures on the number of migrants and refugees with TB in Tak province are unavailable as the national Thai public health surveillance system does not collect data from non-governmental treatment providers. Yet, information collected from Thai government hospitals shows

that for the period of 2006-2011 most of the TB cases in the province were in the Mae Sot border district and of the TB patients in the Mae Sot area more than half were non-Thais (Iemrod & Kavinum, 2015). National level estimates show that Myanmar is much more heavily burdened by TB, TB/HIV and multidrug-resistant tuberculosis (MDR-TB) than Thailand (World Health Organization, 2014a). In 2013, TB prevalence was higher in Myanmar (473/100,000) than Thailand (149/100,000) (World Health Organization, 2014a). Estimated new cases of TB were similarly higher in Myanmar (373/100,000) than Thailand (119/100,000) (World Health Organization, 2014a). In Myanmar more than a quarter (27%) of the TB retreatment cases were multidrug resistant compared with less than one fifth (19%) in Thailand (World Health Organization, 2014a). Almost a third of the TB patients in Myanmar are co-infected with HIV compared to 15% in Thailand (World Health Organization, 2014a). Rates for TB mortality excluding TB/HIV are also four times higher in Myanmar (49/100,000) than in Thailand (12/100,000) (World Health Organization, 2014a).

This research project aims to examine the processes through which migrants and refugees access treatment for TB, TB/HIV and MDR-TB in Tak province as well as identify associated barriers and enabling factors. Here access is defined as “an opportunity to have health care needs fulfilled” (Levesque et al., 2013, p. 4). We approach the concept of access from the perspective that it is a dynamic interplay between population needs and the health system. Previous research on access to antiretroviral therapy for migrants in Thailand identified challenges largely related to “migrants’ marginalized status in the host country”, specifically: difficulties getting health insurance and work permits, arrest by the police, treatment cost, discrimination,

language, challenges leaving work to go to the clinic, social support and taking medicine at work (Saether, Chawphrae, Zaw, Keizer, & Wolffers, 2007, p. 1005). Telleman Saether et al. (2007) identified that migrant research participants from Mae Sot had comparatively more challenges accessing healthcare than participants from Chiang Mai and Bangkok. In this article we build on previous literature by describing access to TB treatment for migrant and refugee populations and identifying the complexities associated with overlapping barriers to care (Hemhongsra et al., 2008; Iemrod & Kavinum, 2015).

Methods

Conceptual framework

In the field of population health conceptual frameworks are developed to help explain complex processes. A conceptual framework identifies a group of variables and describes the relationship between variables that contribute to a phenomena (Carpiano & Daley, 2006). To examine the concept of access, we sought a theoretical framework. Access to health care models have been developed to describe the steps individuals go through to receive care as well as the supply and demand characteristics. We selected a conceptual framework developed by Levesque et al. 2013, which draws on the work of many theorists including Andersen (1995) and Pechanski & Thomas (1981). The strength of Levesque et al.'s 2013 model in the context of our project on access to healthcare for migrants is that it looks at both the healthcare system and the population. Levesque and colleagues (2013) conceptualize that access is related to both health care system accessibility and the ability of the patient population to interface with the system

in order to gain care. Levesque et al. (2013) utilize dimensions of health care system accessibility and population ability to further delineate factors that contribute to healthcare access. The five dimensions of accessibility are: 1) Approachability; 2) Acceptability; 3) Availability and accommodation; 4) Affordability; and 5) Appropriateness (Levesque et al., 2013). Ability is divided into five parallel dimensions: 1) Ability to perceive; 2) Ability to seek; 3) Ability to reach; 4) Ability to pay; and 5) Ability to engage (Levesque et al., 2013). Levesque et al.'s original model is presented in figure 2.1.

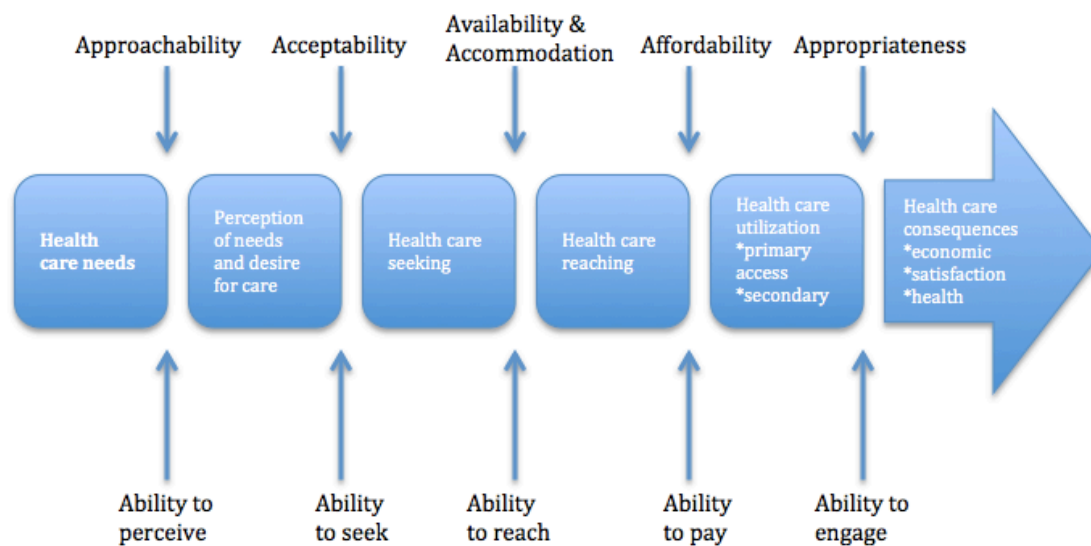


Figure 2.1 A conceptual framework of access to healthcare as developed by Levesque et al (2013).

Inclusion and exclusion criteria

For this research project migrant is defined as an individual who has resided in a foreign country for more than one month or who has crossed a national border to access

essential services, irrespective of the causes, voluntary or involuntary and the means, regular or irregular used to migrate. Individuals who have received refugee status are not considered migrants. This description is adapted and modified from a definition used by the International Organization for Migration. Documented migrant is used to describe someone who has sufficient paperwork to be able to travel legally. Undocumented migrant refers to an individual that does not have the necessary documentation. We sought migrant and refugee patients and non-patients to participate in this study. Our inclusion criteria for migrants were that they were currently living along the border, either as a migrant in Thailand or living in Myanmar and crossing into Thailand and for refugees was that they resided in a refugee camp in Tak province. Our general inclusion criteria for both groups were that they were: 20 years of age or older; sufficiently fluent in either spoken English, Burmese or Karen to participate; and willing to provide consent to participate in the study. We further disaggregated groups by gender and health status, with the respective additional inclusion criteria of: having a confirmed case of TB, MDR-TB or TB/HIV; or not having a confirmed or suspected case of TB.

We approached key informants to participate in this project who were either staff in organizations providing TB treatment or public health professionals. To be included in the study potential participants needed to be working in a care provision or policy capacity with an organization that provides TB/HIV and TB treatment to refugees and migrants in Tak province or working with the Tak provincial public health department or another organization that contributes to infectious disease surveillance. Age (20 years or older), sufficient fluency in either spoken, Thai, English, Burmese or Karen and willingness to provide consent were the additional general inclusion criteria for key

informants. Participants who did not meet the inclusion criteria were excluded from the study.

Data collection

The objective of our research project was to identify the processes through which migrants and refugees access TB treatment in Tak province and enter into the surveillance network. Qualitative methods provided us with the opportunity to explore migrants' and refugees' interpretation of healthcare access as well as their self-identified opportunities for action in situations where they are (Williams & Elliot, 2013). Collecting information from patients and health care providers allowed us to gain multiple perspectives on perceived barriers and enabling factors for TB treatment.

In the summer and fall of 2014, we collected data through key informant interviews and focus group discussions (FGD). Prior to data collection all participants consented to participate. We collected information from 12 key informants who were providing medical or supportive care to TB patients or who were working in public health in Tak province. We approached health service providers and public health surveillance specialists by email and invited them to participate in the project. Our discussion guide examined TB surveillance and treatment for migrant and refugee populations as well as organizational responsiveness to patient challenges. NT conducted the interviews in English and in Thai with the help of an interpreter.

We also held 11 FDGs with TB, TB/HIV and MDR-TB patients and four FDGs with non-patients. Table 2.1 provides information on the composition of the FDGs. We recruited patients from TB clinics run by SMRU, a Thai government hospital, and PU-

AMI, an organization that provides TB treatment in the refugee camp. SMRU is a research unit affiliated with the Faculty of Tropical Medicine, Mahidol University, Bangkok that provides treatment services to refugee and migrant populations in Tak province. SMRU's TB program is funded by the United Kingdom Department for International Development. Clinicians and clinic staff from all three organizations told eligible patients about the study and informed interested individuals of the time and location of the FGD. We held the FGDs in an area that was separate from where clinical services were being delivered at the Mae Sot Hospital, the refugee camp TB village and the SMRU TB village. We conducted the FGDs with non-TB patients in the refugee camp and at two community health posts in greater Mae Sot. Staff from PU-AMI and World Vision Thailand assisted in recruiting non-patient participants by informing individuals of the study as well as the time and location of the discussion. Most of the non-patients that participated in our research were also community health volunteers.

Table 2.1 Composition of focus group discussions

FGD	Location	Type	Number of participants	Description
1	Mae La TB village	Men with TB	6	Refugees and Migrants
2	Mae La TB village	A man and woman with active TB	2	Refugees
3	Mae La TB village	Women with TB	5	Refugees and migrants
4	Mae La TB village	Men who do not have TB	7	Refugees
5	Mae La TB village	Women who do not have TB	8	Refugees
6	SMRU TB village	Women with TB	5	Migrants
7	SMRU TB village	Men with TB	7	Migrants
8	SMRU TB village	Women with TB/HIV	7	Migrants
9	SMRU TB village	Men with TB/HIV	8	Migrants
10	SMRU TB village	Women with MDR-TB	6	Refugees and migrants
11	SMRU TB village	Men with MDR-TB	7	Refugee and migrants
12	Mae Sot Hospital	Women with TB	3	Migrants
13	Mae Sot Hospital	Women and Men with TB	5	Migrants
14	Community health post	Men who do not have TB	8	Migrants
15	Community health post	Women who do not have TB	8	Migrants

Our focus group discussion guide consisted of four domains of inquiry: process to access treatment, barriers, enabling resources and treatment adherence. We also utilized probes to elicit more contextual information from participants on issues related to

healthcare access such as gender, language and legal status. Two interpreters assisted with the FGDs by providing simultaneous translation from Karen and Burmese languages into English.

Data analysis

Following data collection, NT transcribed the audio files from the interviews that were done in English and two research assistants translated and transcribed the FGDs and interviews that were conducted in Karen, Burmese and Thai languages. After transcription, we analyzed the data using thematic analysis. We uploaded transcripts into the NVivo software program and subsequently coded the transcripts using both *a priori* and emergent codes. We reorganized the codes into themes or “implicit and explicit ideas” (Guest et al., 2012, p. 13). Data saturation for this project was reached when we ceased to identify new themes that are pertinent to the research question. We used data triangulation, the use of multiple methods to seek the same information from different perspectives, to help attain data saturation (Fusch & Ness, 2015). To further triangulate the data we returned to the field in June 2015 to present the preliminary results to stakeholders and to seek their feedback.

As a second step in the qualitative analysis, we identified barriers and enabling factors by population and separated the information for migrants and refugees. We then mapped the barriers and enabling factors for each population onto Levesque et al.’s (2013) conceptual framework to examine the fit between our data and the framework. We identified several themes that did not fit the framework and decided to revise the model.

In reporting the results we first identify the overarching thematic domains and then we further discuss the findings by population, first reporting the findings for refugees followed by those for migrants. To help provide insight into the legal, demand and supply factors that influence migrant's access we report according to legal status, population ability and health care system characteristics. We use personal quotes to allow the participants to share their interpretation based on their own experience while providing insight on the contextual and structural factors that shape it (Williams & Elliot, 2013). In order to mask identifiable information, we use pseudonyms for focus group discussion participants and identify interview participants as "key informants."

Ethical considerations

We obtained ethics approval from the University of Ottawa (#H02-14-08), the University of Oxford (538-14) and the Tak Provincial Public Health Office (TK 1/2557).

Results

Barriers and enablers for TB treatment access

In examining barriers and enablers for TB treatment access we identified seven overarching thematic domains namely: financial, TB health services, patient health status, transport, patient beliefs and behavior, legal status and psychosocial support. A list of the barriers and enablers along with the information source is provided in Table 2.2 We found significant differences in access to TB treatment for refugees and migrants. Refugee participants reported fewer barriers to receiving TB treatment as compared to

migrants. The barriers to TB treatment as perceived by refugees, migrants and treatment providers and public health officials, are illustrated in Figure 2.2. The overlapping sections show barriers that were identified by multiple groups. For example, all groups identified these barriers: money/work, delayed care seeking, duration of treatment and comorbidity. Our key informants who provided TB treatment, support services or worked in a public health capacity identified several barriers which were not reported by patients namely: time to diagnosis, denial, patient mobility, and HIV co-infection. There was also considerable overlap in the barriers perceived by migrants and key informants, specifically: housing, language, cost, services not available, police, travel restrictions and limited knowledge.

Table 2.2 Barriers and enabling factors for Migrants and Refugees seeking TB treatment

Thematic Domains	Barrier	Source	Enabler	Source
Financial	Family work responsibilities	Migrant/refugee / KI	Time off work	Migrant
	Money problems	Migrant/refugee / KI	Borrowing money	Migrant
			Community fund	Migrant
	Housing	Migrant/KI	Money Housing and food	Migrant/KI Migrant/refugee/KI
TB Health services	Language	Migrant/KI	Language understood	Migrant/refugee
			Interpreter	Migrant
	Treatment cost	Migrant/KI	Free or low cost services	Migrant/refugee
	Services not avail	Migrant/KI	Available treatment	Migrant/refugee
			Quality services	Migrant/refugee
			Referral communication	Migrant/KI
			Health care workers	Migrant/refugee
	Time to diagnosis	KI		
Duration	Migrant/refugee /KI			
Health status	Commorbidity (alcohol/diabetes)	Migrant/refugee /KI		
	HIV co-infection and stigma	KI		
Transport	Travel restrictions	Migrant/KI	Transport provided by health service provider	Migrant/KI
	Police/documents	Migrant/KI	Employer transport	Migrant
	Travel cost	Migrant	Live closeby	Migrant
Patient beliefs and behaviours	Delayed care seeking	Migrant/refugee /KI		
	Limited knowledge of TB and health system	Migrant/KI		
	Denial	KI		
	Mobility	KI		
Legal status	Undocumented	Migrant	Documents	Migrant
			Health insurance card	Migrant
Psycho social support	No caregiver	Migrant	Psychosocial activities	Migrant/KI
			Family or Community Support	Refugee/migrant/ KI

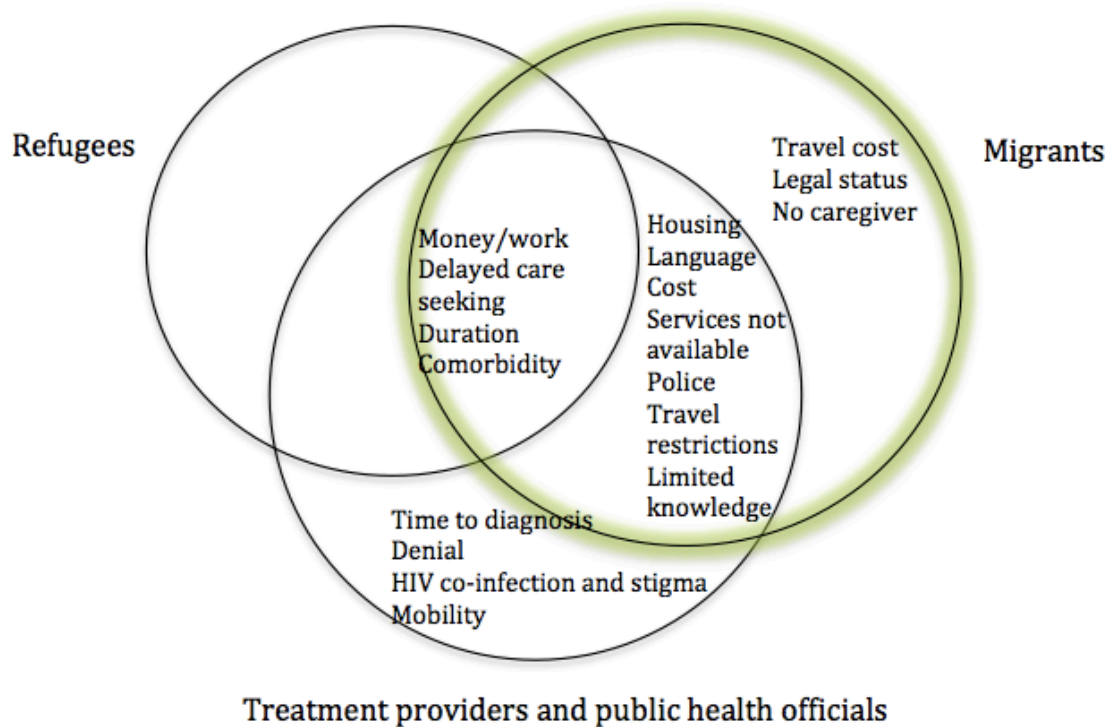


Figure 2.2 Barriers to Tuberculosis Treatment as perceived by refugees, migrants, treatment providers and public health officials

Access to TB treatment for refugees

Refugees reported limited barriers to care as international organizations provide comprehensive health care free of charge in the refugee camp. PU-AMI provides TB services to the general camp population and IOM screens and treats individuals who have been accepted into the resettlement program. TB and TB/HIV treatment is provided at a residential TB village and MDR-TB cases are referred outside the camp to SMRU. PU-AMI provides transportation to SMRU for all referred patients. Treatment at the PU-AMI TB village is provided in Burmese and Karen languages. Participants identified that provision of treatment in languages that they speak was an enabler for accessing

treatment. Medics, a form of community health worker, often speak Karen and provide TB treatment in the TB village under the direction of a Myanmar doctor. “We don't have problem here because all the staffs can speak Karen and the majority of patients use Karen language” (Bway Paw, female TB patient, refugee).

Patients identified psychological support as an enabler to accessing and continuing treatment. In the TB village, staff hold psychosocial events to promote mental well-being among patients. Patients also described benefiting from family support.

Refugees have supportive resources including housing and food that help them to access treatment. While several refugee participants indicated concerns about the financial implications of missed work opportunities associated with TB treatment, most emphasized the buffer provided by food rations and secure housing inside the camp. “For us as refugees, we don't have any special work and we also get free food every month” (Wiya Htoo, male TB patient, refugee).

Key informants and refugee participants reported a few minor barriers to accessing treatment. Several refugees reported waiting until they were very ill before going to a healthcare provider for treatment. Participants also explained that comorbidity, length of treatment for MDR-TB, stigma and denial are minor barriers to treatment for the refugee population. Comorbidity such as alcohol use may make it more difficult or complex to access healthcare. The TB camp in the refugee camp is a dry zone and drinking is prohibited. MDR-TB treatment takes two years and is not available in the refugee camp. Length of MDR-TB treatment may be a barrier for some patients due to the long time they would be separated from their family.

Stigma for TB is declining in the refugee camps as knowledge about the disease increases. As one KI explained that stigma for HIV is considerably higher,

TB is infectious but it can be treated. HIV is infectious plus it can be treated but it's a very long, very long treatment. There's a big stigma among HIV patients inside the community. A thousand times more than TB I think (key informant).

While PU-AMI provides TB treatment to the general camp population, refugees who are relocating to a third country are screened for TB by IOM. Some of the refugees who test positive for TB are in denial as they are asymptomatic. Denial may lengthen the time it takes patients to accept treatment.

Migrant's legal status and access to TB treatment

We found that legal status has important implications for where patients are eligible to receive free or low-cost care. Participants explained that general healthcare entitlements differed between refugees, undocumented migrants and documented migrants who had registered in the Thai migrant health insurance scheme. For example, migrants with health insurance can access TB treatment at the Thai government hospitals. In contrast, migrants without this insurance have to pay directly for treatment at the government hospitals or can access treatment free of charge where a third party donor funds their treatment. "It depends on whether you hold any legal document or not. If you have no legal document and no health insurance then you'll have to pay but those who have it don't need to pay" (Zaw Myine, female non patient, migrant).

A TB village run by SMRU provides free TB, TB/HIV and MDR-TB treatment to migrants regardless of legal status. SMRU also treats refugees who have MDR-TB.

Participants identified legal status as an overarching barrier for migrants from Myanmar who need to travel to access TB treatment in Thailand. Migrants without proper documents are in Thailand illegally and were concerned about their security while travelling to get treatment. Undocumented migrants are more susceptible to police extortion. On the other hand, having the correct documentation permits migrants to travel freely without concern for their personal safety. Documentation ranges from having a day pass to travel in Thailand to having a passport and work permit.

We have a lot of problems. We have to be afraid of the police. If they catch us then we have to pay them, sometimes more than a thousand baht [USD28] and if you can't pay then they will put you in prison and then deport you (Khin Tun, male TB patient, migrant).

Thai police have official and unofficial checkpoints set up near the border. Migrants who lack proper travel documentation are forced to pay police money to let them through the checkpoint. Participants reported being afraid of the police. Paying police was identified by patients, non-patients and key informants as one of the major barriers to accessing TB treatment. The amount of money that police might request ranged from 100 baht (USD 3) to several thousand baht. To put this amount in context, focus group participants reported that the average daily wage of migrant workers is approximately USD3.

Migrant legal status can become more precarious if they are diagnosed with TB. Migrants undergo health screening when they are applying for their work permit or renewing it. TB testing is part of the health screening and one research participant explained that her TB status barred her from getting her work permit renewed.

As a migrant worker we have to renew our passport visa every two years and every year we have to renew our work permit so we have to do health screening. My visa expired in 2014 so I needed to extend it and do the screening. When they found out that I had TB, my boss fired me and I got medication from this hospital. I have to come to this hospital every month for follow up and TB medication (Chit Myo, female TB patient, cross border migrant).

Migrant's ability to seek and reach TB treatment

While we sought to identify barriers and enablers to accessing treatment in Tak province, we discovered that there is a large geographic catchment area for migrant TB patients that extends 500km south to Bangkok and 450km east to Yangon, Myanmar. As the catchment area stretches beyond provincial and national boundaries, many of the factors that influence access for migrants also exist outside of the province. Some FGD participants reported complex pathways to TB treatment that began outside of Tak's provincial jurisdiction. For example, several patients with MDR-TB who came from outside of Tak province described a lengthy search to find suitable treatment which involved seeking and in some cases receiving treatment at multiple locations. Travel is especially challenging for patients coming from rural mountainous regions of Kayin state, Myanmar as they may need to hike out of their village to seek shared motor transport to the border, hire a boat to take them across the river and then secure additional shared transport to arrive at a TB treatment provider.

We found that although most migrant patients did not initially know where to seek TB treatment in Mae Sot, this does not affect their ability to seek care as they were

able to seek referral services from Mae Tao Clinic (MTC). MTC, a well known clinic that provides free healthcare services to migrants, refers TB patients to SMRU for treatment. Some of the migrant participants in our study went directly to the Thai government hospital for TB treatment.

Some of the migrant patients in the focus group discussions described waiting until they were very ill to seek treatment. Patients explained that they delayed accessing treatment due to family and work responsibilities. We found that most participants would need to take time off without pay to access treatment. Loss of income was identified as a significant barrier to treatment by TB patients who are the sole income earner in their household.

The problem is as a man you are the head of the family and you have to work in order to get some income for your family to survive. When you come and get treatment there is a problem for daily expenses and it is not easy to go back and look after your family who live very far from you in the village (Zaw Lwin, male MDR-TB patient, cross-border migrant).

We found that there is a significant distinction between documented migrant workers and cross border migrants who reside in Myanmar but come across the border to Thailand for work or to access healthcare services. The distinction is important as cross border migrants are less likely to be registered as migrant workers in Thailand and are subsequently less likely to be enrolled in the migrant health insurance scheme that provides registrants with access to low cost healthcare at Thai government hospitals.

Our results suggest that access to TB treatment for migrants is closely related to available resources to reach treatment centers and pay for treatment. Migrants who have

sufficient financial means can access care at the Thai government hospital and pay directly for the services. Eka, a female migrant TB patient explains, “We have to think...overall about accommodation, treatment, food, etc. we have to think and find appropriate place to go”. We found that for migrants without travel documents, travel to reach TB treatment services is complicated by financial, logistical and legal issues. Travel costs are a barrier to accessing treatment, especially for those who are travelling a long distance from inside Myanmar. Amounts paid for transportation varied by participant and one person reported paying 150,000 kyat in travel costs (USD 135). This is significant as it represents ten percent of the GDP per capita in Myanmar which was USD 1126 in 2012 (UN Data, 2015).

For those who live close to this clinic for example, if they live inside Mae Sot or Myawaddy it might not cost that much for them (to travel) but imagine someone who is from very deep inside Burma, in a distant area of Karen, Kayan or Shan state, it's a long distance to come and it will cost too much (Aye Maung, male MDR-TB patient, cross-border migrant).

For cross border migrants like Aye Maung it is sometimes less expensive to travel to Thailand for treatment than to venture further inland in Myanmar for care. We found that there are contextual differences for cross border migrants depending on where they need to travel through to cross over into Thailand. One participant indicated that it may be necessary to seek a guide to pass through military controlled areas in Myanmar on one's way to Thailand.

Once in Thailand lack of documentation contributes to augment travel costs and undocumented migrants mentioned paying higher transportation costs in order to avoid

Thai police checkpoints. There are travel restrictions for migrants and refugees. Migrants require a passport or day pass from Myanmar to be able travel within Tak province.

Travel restrictions for refugees also affect migrants who are trying to access care in the refugee camp. In 2014, restrictions for entering and leaving the camp were more heavily enforced due to the political climate. Strict travel restrictions also make it difficult for undocumented migrants to return to clinics for follow up care. Transport provided by one's employer or a health service provider helps migrants to access treatment without having to worry about police checkpoints or travel costs. Living close to the treatment is another enabling factor.

Migrants described the strategies that they used to gather the resources necessary to seek and obtain treatment. Some used their wages and savings or received funds from their families. Participants also reported borrowing money from friends or their bosses in order to pay for treatment. We found that flexible employers, who permitted their employees to take time off to get TB treatment, also enabled migrants' to seek and continue treatment. Beyond financial resources and employer flexibility, migrant patients indicated that the support of family and friends as well as accommodations and food helped them to access and continue TB treatment. Families and friends provided encouragement and in some cases helped the patient search for a TB treatment provider. Having a relative in the refugee camp enabled undocumented migrants to access camp health services by coming in and staying with their relative.

I live in the village in Burma. I went to visit my friend and her husband had TB at that time but I was healthy. After I came back home I coughed a lot so I suspected

that I had TB. I have an aunt in Maela refugee camp and she asked me to come and get treatment in the camp. (Thinza, female TB patient, migrant)

Housing and food help migrants access treatment as they consequently do not need to worry about these basic needs. SMRU has set up a TB village in Tak province which provides housing and food to patients. In addition, at the time of data collection World Vision Thailand had a community care program that provided housing and food to TB patients. PU-AMI also provides housing and a limited amount of food to migrants who seek treatment in the refugee camp.

Accessibility of the healthcare system for Migrants

Migrants indicated that where treatment services were provided in a language that they could understand or an interpreter was present, their ability to access services was enhanced. Where health services are provided only in the Thai, language was identified as a barrier.

I don't understand the language so I don't know what to do next after I finished the fifteen days medication. I couldn't communicate so I didn't ask what disease I have at that time, I just took the medication that they gave me and realized that I feel better.... When I arrived back they told me that I had TB, I don't know which part of my body has TB, I got back pain so I thought that it might be bone TB....

The problem for me is the language because I can't speak Thai. (Lwin Aung, female TB patient, cross-border migrant)

We found that in Tak province, availability of treatment for TB varies by legal status, comorbidity (TB/HIV) and drug resistance (MDR-TB). Migrant's options for

healthcare services narrow as TB care becomes more complex. We identified seven locations where migrants without documentation could access treatment for drug resistant TB, compared with one location for TB/HIV and one location for MDR-TB. It is important to note that SMRU is the only organization that provides TB/HIV and MDR-TB treatment to undocumented migrants. Treatment for MDR-TB is provided to migrants with health insurance at the Mae Sot district hospital. However, the amount of available funding limits the number of MDR-TB treatments that are available at the hospital and SMRU. SMRU relies on donor funding to finance its TB treatment program. At the time of this research SMRU had met the quota for MDR-TB patients and was applying for new funds.

Availability of free or low cost treatment services for TB, TB/HIV and MDR-TB in Tak province is an enabler for migrants to access treatment. While TB treatment is available to documented and undocumented migrants in Tak province, participants reported lack of affordable and accessible treatment in Bangkok and within Myanmar contributed to their decision seek care in Tak province. MDR-TB treatment is very expensive and would be unaffordable for most migrants if they had to pay for it directly. One course of treatment is 200,000 Thai baht (USD 5,950). It is not only the cost for treatment that is a barrier but also the fees associated with tests necessary to determine that they have TB. “The result came out that I couldn't continue with the medication that I was taking and MDR-TB treatment was not available in Burma that's why I came to Mae Tao Clinic” expressed Ye Htun a male migrant MDR-TB patient.

Several migrant patients reported traveling to different healthcare providers in search of effective TB treatment before coming to Tak province. Patients who had

received previous TB treatment that was not effective, explained that they had to travel to get treatment. Migrants perceived treatment for TB available in Tak province is of high quality. This includes care available at the Thai government hospital, NGO healthcare providers and in the refugee camp. “We heard that this hospital provides good treatment and services so we came here” (Mya Hla, female TB patient, cross-border migrant).

We found that health care workers and community healthcare volunteers play an integral role in providing continuity of care through referrals, psychosocial support in addition to treatment services. Health care workers arrange comprehensive care including treatment, housing and food provision for migrant patients. In some cases they also provided patients with pocket money for living expenses. Overall patients emphasized the importance of the encouragement that the healthcare workers provided.

While taking this medication we are really tired and sometimes we want our family's love and care but they can't come and take care of us in person. The most important people while we are here are the health care providers, they care, encourage, and help us with every single thing they can. Because of them we are still alive and have hope. (Cho Htway, female MDR-TB patient, migrant)

We found that provision of supportive care at the community level has the potential to enhance accessibility as migrants don't need to travel and subsequently can avoid the travel associated barriers to care. Community health volunteers live in migrant communities and provide health promotion, treatment for mild conditions and suggestions on where to access treatment. In Tak province, World Vision had a TB program which was run by community health volunteers and supported migrants through the dissemination of information about TB, locating and testing potential TB patients, and

providing transport to the hospital. The program was run through community health posts in migrant communities and also provided directly observed treatment, short-course (DOTS) to patients in their community so that they could continue working.

Referrals for Migrants with TB, TB/HIV and MDR-TB are another enabler for accessing treatment. These include both official referrals through direct communication between organizations and indirect referrals where patients are told where they can get treatment. Patients are referred to treatment services in Tak province from within the province, within the country and from inside Myanmar.

Discussion

Overlapping perspectives on barriers to care

Our results that many of the barriers to care experienced by migrants were also identified by KIs are not surprising as the interviewees were often working closely with migrant TB patients. KIs however mentioned several barriers related to health care provision and patient characteristics, which were not cited by migrants such as patient mobility. This was identified as a concern due to the potential of drug resistance from missed doses and subsequently reduced mobility was included as an eligibility criteria for care by some care providers. We perceive that this is an important dimension of TB treatment eligibility and may deserve future inquiry.

Integrating study results into the conceptual framework

We used the conceptual framework for access to healthcare developed by Levesque et al. (2013) to organize and interpret the barriers and enabling factors that help migrants to access treatment for tuberculosis. Our results suggest that migrants' ability to engage with the healthcare system is related to legal status, their socio-economic situation and the financial and non-financial resources that are available to them. Participants in our focus group discussions described weighing the associated costs before making a decision to seek care. Legal status has a huge influence on migrants' ability to perceive, seek, reach, pay and engage in healthcare services. For example, our research suggests that migrants' who do not have health insurance may not consider themselves eligible to access low-cost healthcare and Thai government hospitals. Lack of appropriate legal documentation makes it difficult to seek and reach health services as well as to return to treatment centers for follow-up care.

Levesque et al.'s framework is also useful to help conceptualize health care system accessibility for TB treatment (2013). For example, we found that referrals from partner organizations increase approachability for patients who are seeking TB treatment. Organizations in Tak province provide TB care in Burmese and Karen languages and the Thai hospital provides a translator which increases acceptability of care. In Tak province TB treatment for refugees and migrants is available, affordable and appropriate. Nonetheless we found that lack of available, inexpensive and effective TB treatment in Myanmar and Bangkok contributed to migrants' decisions to seek treatment along the Thailand-Myanmar border.

Our results suggest that for refugee and migrant populations legal status is a factor that impacts the population's ability to engage with the health care system in efforts to gain access to TB treatment. Legal status does not fit neatly into Levesque et al.'s framework as is not a characteristic of the population nor of the health system but plays an important role in shaping program eligibility on the supply end and affects all of the five theorized population "abilities" (Levesque et al., 2013). Given the prominence of legal status we propose to amend the framework to include legal status as an intermediary factor between population level abilities and health system accessibility. This modification makes the model more relevant to migrant and refugee contexts where legal status is an important intermediary factor that helps determine who can access care and what they can access.

A second challenge that we identified with the Levesque et al. framework is that as it is linear it fails to represent one of the more iterative processes that we observed (Levesque et al., 2013). Many of the migrants who participated in our project had previously received TB treatment outside of Tak province. We observed that there is a cycling in and out of treatment in search for care that is appropriate and effective. Therefore, we propose to integrate treatment cycling into the framework through a series of arrows from appropriateness to availability. Figure 3 shows the revised framework with our additions in orange.

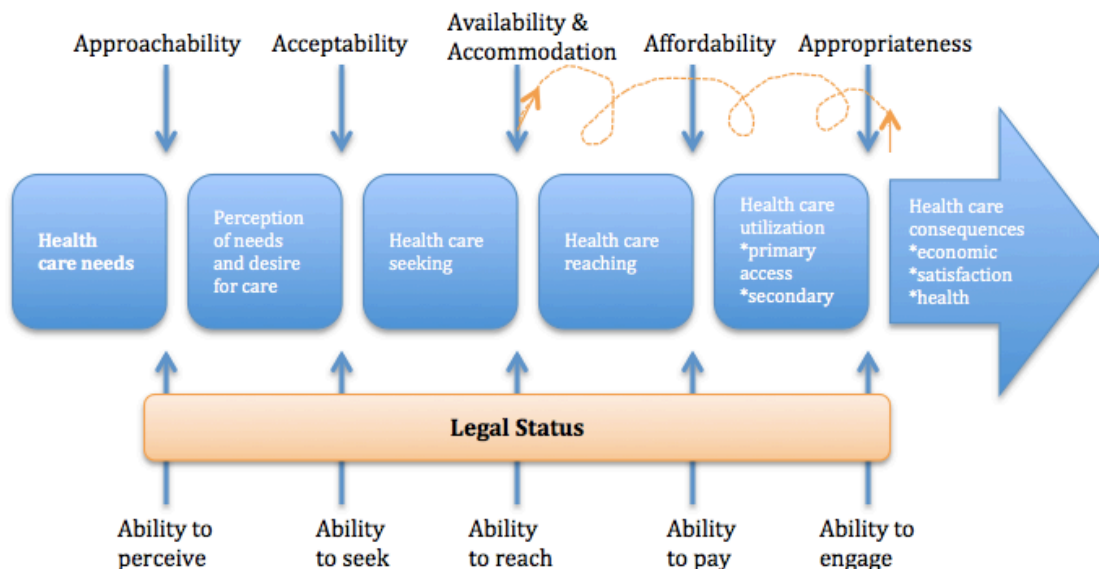


Figure 2.3 A conceptual framework for access to healthcare for migrants and refugees. Additions to the original model are shown in orange. The arrows indicate treatment cycling as individuals find available treatment but later learn that the treatment is not appropriate and must again search for available treatment.

By making legal status and treatment cycling explicit, we anticipate that this revised model can be used as an assessment tool for organizations who are delivering health services to migrant and refugee populations. Treatment providers in regions experiencing heightened migration such as Europe may find this model useful as it has the potential to help generate baseline information on treatment barriers and potential mitigating factors. Specifically, organizations can consider population ability to access care, healthcare accessibility, legal status and implications of treatment cycling in their service delivery plans. Based on the data we collected, it is evident that health service providers in Tak province, Thailand are already considering the socio-economic situation

of their patients and are providing supportive care including accommodation, food and psychosocial support to help their patients complete treatment.

In further considering a population's ability to access services, providers should consider the economic demands of treatment and the available financial and non-financial resources. We found that migrants in Tak province can access free TB treatment but still have associated economic demands such as lost wages and travel costs. Migrants' who participated in this research identified social networks, inclusive of family members, neighbors, friends and monks, as an important resource that they utilized to enhance their ability to seek, reach and pay for care.

Limitations

It is important to note that the migrants who participated in this study are the ones who effectively navigated the barriers to care and were successful in obtaining care in Tak province. The geo-political context along the Thailand-Myanmar border is evolving. As a result, this study's findings should be interpreted in relation to the summer and fall 2014 data collection period. Since we completed data collection there have been changes to the government migrant health insurance scheme which we anticipate may, over time, affect access to healthcare.

Conclusion

In Tak province, Thailand migrant and refugee's ability to access TB treatment is complex. Access is influenced by both supply and demand characteristics within the province and beyond. Given the large geographic catchment area for patients many

of the factors that influence access to treatment exist outside of the province.

Migrants who travelled from Myanmar and other locations in Thailand reported a lack of available, affordable and appropriate care in those settings. We found that migrant patients draw upon their social network, financial resources and supportive services provided by local organizations to navigate a pathway to treatment. This study is relevant for researchers and practitioners who work with migrants and refugees as it demonstrates that access to healthcare for these populations occurs at the interface of health system accessibility, population ability and legal status. Our proposed revised conceptual framework for access to healthcare, which incorporates legal status and the cyclical pathways through which migrants access care, has the potential to resonate in other contexts where legal status influences entitlement to healthcare. We recommend that treatment providers in other jurisdictions ask their patients about their pathways to treatment, identify barriers and work collaboratively to improve access to care.

Article 3. Treating the invisible: Gaps and opportunities for enhanced TB control along
the Thailand-Myanmar border

Naomi Tschirhart, Sein Sein Thi, Lei Lei Swe, Francois Nosten, Angel M. Foster

Author note

Naomi Tschirhart, Faculty of Health Sciences, University of Ottawa, Shoklo Malaria Research Unit, Mahidol-Oxford Tropical Medicine Research Unit, Faculty of Tropical Medicine, Mahidol University; Lei Lei Swe, Shoklo Malaria Research Unit, Mahidol-Oxford Tropical Medicine Research Unit, Faculty of Tropical Medicine, Mahidol University; Sein Sein Thi, Shoklo Malaria Research Unit, Mahidol-Oxford Tropical Medicine Research Unit, Faculty of Tropical Medicine, Mahidol University; Francois Nosten, Shoklo Malaria Research Unit, Mahidol-Oxford Tropical Medicine Research Unit, Faculty of Tropical Medicine, Mahidol University, Centre for Tropical Medicine and Global Health, Nuffield Department of Clinical Medicine, University of Oxford; Angel M. Foster, Faculty of Health Sciences, University of Ottawa.

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Abstract

Background

In Thailand's northwestern Tak province, contextual conditions along the border with Myanmar pose difficulties for TB control among migrant populations. Incomplete surveillance data, migrant patient mobility, and loss to follow-up make it difficult to estimate the TB burden and implement effective TB control measures. This multi-methods study examined tuberculosis, tuberculosis and human immunodeficiency virus co-infection, and multidrug-resistant tuberculosis treatment accessibility for migrants and refugees in Tak province, health system response, and public health surveillance.

Methods

In this study we conducted 13 interviews with key informants working in public health or TB treatment provision to elicit information on TB treatment availability and TB surveillance practices. In addition we organized 15 focus group discussions with refugee and migrant TB, TB/HIV, and MDR-TB patients and non-patients to discuss treatment access. We analyzed the data using thematic analysis and created treatment availability maps with Google maps.

Results

The study identified surveillance, treatment, and funding gaps. Migrant TB cases are underreported in the provincial statistics due to jurisdictional interpretations and resource barriers. Our results suggest that TB/HIV and MDR-TB treatment options are limited for migrants and a heavy reliance on donor funding may lead to potential funding gaps for migrant TB services. We identified several opportunities that positively contribute to TB control in Tak province: improved diagnostics, comprehensive care, and

collaboration through data sharing, planning, and patient referrals. The various organizations providing TB treatment to migrant and refugee populations along the border and the Tak Provincial Public Health Office are highly collaborative which offers a strong foundation for future TB control initiatives.

Conclusions

Our findings suggest the need to enhance the surveillance system to include all migrant TB patients who seek treatment in Tak province and support efforts by stakeholders on both sides of the border to continue to share data and engage in collaborative planning on TB, TB/HIV, and MDR-TB treatment provision for migrant populations.

Background

Tuberculosis (TB) control across international borders has been identified as a challenge in multiple geographic contexts (Coker, Atun, & McKee, 2004; Dara et al., 2012; Matteelli et al., 2016; Noeske, Foe, & Kuaban, 2016). Migrants with TB may experience challenges accessing early TB diagnosis, lack of continuity of care, and difficulties accessing healthcare in the new country (Dara et al., 2012). From a surveillance perspective, data collection remains a barrier to effective TB control as public health departments struggle to document the number of TB cases among mobile patients in their jurisdiction as well as to share and collaborate with their counterparts on the other side of the national border. Surveillance, defined as the “continual analysis, interpretation, and feedback of systematically collected data” can be challenging in border regions (Stop TB Partnership, 2016).

In South-East Asia increased mobility across international borders poses difficulties for effective infectious disease control (Coker, Hunter, Rudge, Liverani, & Hanvoravongchai, 2011). Thailand is host to 2.7 million migrant workers from the neighboring countries of Cambodia, Lao Peoples’ Democratic Republic, and Myanmar as well as 127,000 persons living in shelters near the Thailand-Myanmar border (Huguet, 2014). It is expected that migration into Thailand will increase with the economic integration of the Association of Southeast Asian Nations (ASEAN) and the ASEAN Economic Community (AEC) established in 2015. While the AEC has introduced policies to encourage labour mobility for skilled workers, it is anticipated that migration of low skilled workers between ASEAN countries will also increase due to freer trade and associated investment and economic development (Rynhart & Chang, 2014).

Increasing numbers of migrants have implications for TB control in Thailand as well as the potential augmented need for health care services in the border regions (Huguet, 2014; World Health Organization Thailand, 2013). Migrants may be vulnerable to illness due to poor living and working conditions and challenges accessing healthcare (Huguet, 2014).

Multi-drug resistant tuberculosis (MDR-TB) has been identified as an emerging infectious disease in South-East Asia, yet because of weaknesses and differences in the national surveillance systems in the region it is difficult to estimate and compare the burden for this and other emerging infectious diseases (Coker et al., 2011). Under reporting of emerging infectious disease has the potential to hamper prevention and an effective public health response (Coker et al., 2011). In Thailand lack of complete surveillance data, inclusive of migrant cases, has been identified as a hindrance to health policy and health services development (Huguet, 2014). A 2007 demonstration project collected TB data from all government and non-government care providers in Tak province including non-Thai patient data, however the authors indicated that data are not uniformly reported to the National TB Programme (Hemhongsra et al., 2008). Along the Thailand-Myanmar border limited coordination among stakeholders, unstructured information sharing, loss to follow-up, and limited resources have been identified as challenges to cross-border TB control as well as for control within the respective Thailand and Myanmar border regions (Kaji et al., 2015).

Tak province, Thailand is situated in the country's northwestern region and shares a 500km border with Kayin state, Myanmar. In Tak province public health surveillance is overseen by the Tak Provincial Public Health Office (Tak PHO) with guidance on TB

surveillance from Thailand's National Tuberculosis Programme. Historical surveillance data from Tak province from 2006-2011 indicate that most of the TB cases occurred in Mae Sot and the majority of these were among non-Thais (Iemrod & Kavinum, 2015). Mae Sot is the city in Tak province which is closest to the Thailand-Myanmar border. A 2007 study also found that the majority of TB cases (65%) were among non-Thais in Tak province and estimated the prevalence to be 109 per 100,000 for Thai citizens, 340 per 100,000 for Myanmar refugees, and 150 per 100,000 for Myanmar migrants (Hemhongsat et al., 2008). On the Myanmar side of the border, directly across the border from Tak province, in Myawadee township the case notification rate of new smear positive TB cases was 178/100,000 in 2012 (World Health Organization Thailand, 2013).

In Tak province five Thai government hospitals and three organizations, *Première Urgence - Aide Médicale Internationale (PU-AMI)*, the *Shoklo Malaria Research Unit (SMRU)*, and the *International Organization for Migration (IOM)*, treat migrants and refugees who have TB. Access to healthcare is closely related to legal status and some organizations provide TB treatment specifically for migrants and/or refugees who are not eligible to receive low cost care from the Thai government system. All of the organizations that provide TB treatment to migrants and refugees in Tak province belong to the *Tak Tuberculosis Initiative (TTBI)* which provides a forum for organizations to share data and develop shared strategies for TB control in the border region. Beyond the TTBI there is additional evidence of cross-border collaboration as official transfer forms have been developed for cross border referral. While key informants in a 2014 study indicated that the border referral system needs further improvements to be of practical

use, the study documents that preliminary border referral discussions have begun (Kaji et al., 2015).

Our overall research project aimed to examine TB treatment accessibility for migrants and refugees in Tak province, provincial TB surveillance, and health system response to treatment barriers. We have published two manuscripts from this project. The first documents pathways to treatment and travel with TB (Tschirhart et al, 2016a). The second focuses on access to TB treatment for migrants and refugees (Tschirhart et al, 2016b). In this article we discuss the gaps and opportunities for improved TB control in the border region of Tak province and examine TB control from a wider lens through emphasis on surveillance. We use the term “TB control” throughout to indicate TB care and prevention efforts and acknowledge that TB control is not solely dependent on public health specialists but also relies to the resources of TB patients and their families (Stop TB Partnership, 2016).

Methods

Our team conducted primary data collection in Tak province, Thailand from August-October, 2014 with one additional follow up interview in December 2015. To collect information from different perspectives, we organized interviews with key informants (KIs) working in public health or TB treatment provision, as well as focus group discussions (FGDs) with TB patients and non-patients, and a survey with community health volunteers. As our participants had varying levels of literacy and legal statuses within Thailand we opted to collect verbal consent from all participants. We read the consent form to participants and documented their verbal consent. Collecting verbal

consent allowed us to further safeguard participants' identities, as we could avoid carrying around documentation with the names of informants. We have detailed our research methods elsewhere (Tschirhart et al., 2016a, 2016b). This paper reports on the findings from the interviews and FGDs that are relevant to TB control.

Data collection

Thirteen individuals who were providing TB treatment, supportive care, or were working in a public health capacity participated in the KI interviews. We compiled a list of organizations working on TB and public health in the border region and recruited KI participants at these organizations through email and phone communications. To be eligible to participate individuals had to be working in an organization that contributes to infectious disease surveillance or that provides TB treatment or supportive care to migrants and/or refugees in Tak province. We interviewed each KI their place of work and the majority of interviews took place in the Mae Sot border district of Tak province where many organizations working along the border have administrative offices. NT led the interviews with assistance from a Thai interpreter when needed. The interviews focused on TB, TB/HIV, and MDR-TB treatment and surveillance based on the participant's professional experience. Specifically, we asked clinic staff and administrators about their TB care programs, patient barriers to care, and responsive actions aimed at improving access to care. We asked participants who collected and analyzed TB records about data collection practices, associated challenges, and changes that had been implemented in the previous two years.

We held 15 FGDs with migrants and refugees who were living or seeking healthcare in Tak province. The groups were disaggregated by health status, gender, and migrant or refugee identification. For this project we define migrants as individuals who have resided in a foreign country for more than one month or who have crossed a national border to access essential services. We use the term undocumented migrant to refer to individuals that do not have the necessary documentation to travel legally. In recruiting refugees, we included individuals who had received refugee status in the refugee camp. We held 11 FGDs with TB, TB/HIV, and MDR-TB patients (n=61) and 4 FGD with non-patients (n=31). Table 3.1 provides descriptive information on the composition of the FGDs.

Table 3.1 Description of Focus Group Discussions

FGD	Location	Description	Number of participants	Participant status
1	Mae La TB village	Men with TB	6	Refugees and Migrants
2	Mae La TB village	A man and woman with active TB	2	Refugees
3	Mae La TB village	Women with TB	5	Refugees and migrants
4	Mae La TB village	Men who do not have TB	7	Refugees
5	Mae La TB village	Women who do not have TB	8	Refugees
6	SMRU TB village	Women with TB	5	Migrants
7	SMRU TB village	Men with TB	7	Migrants
8	SMRU TB village	Women with TB/HIV	7	Migrants
9	SMRU TB village	Men with TB/HIV	8	Migrants
10	SMRU TB village	Women with MDR-TB	6	Refugees and migrants
11	SMRU TB village	Men with MDR-TB	7	Refugee and migrants
12	Mae Sot Hospital	Women with TB	3	Migrants
13	Mae Sot Hospital	Women and Men with TB	5	Migrants
14	Community health post	Men who do not have TB	8	Migrants
15	Community health post	Women who do not have TB	8	Migrants

We recruited patients from TB clinics operated by SMRU, the Mae Sot Hospital, and PU-AMI. TB doctors and clinic staff told eligible individuals about the study and conveyed that participation was voluntary and that their decision to participate would not affect

their care. Doctors and clinic staff informed interested patients of the location and time of the FGD. To be eligible to participate, patients needed to have a confirmed case of TB, MDR-TB or TB/HIV. We recruited non-patients with the assistance of PU-AMI in the refugee camp and World Vision Thailand (WVT) in migrant residential communities in Mae Sot. Program staff informed eligible participants of the voluntary study as well as the time and place that the FGD would occur.

FGDs took place at the SMRU TB village, the PU-AMI TB village, the Mae Sot Hospital, and at two World Vision migrant health posts. In each location we conducted the FGDs in a separate area from where treatment was being given. After participants consented to participate, NT conducted the FGD with assistance from two interpreters who translated from English to Burmese and Karen languages. FGDs explored participants' actual or perceived ability to access TB treatment as well as the related barriers and enabling factors. Participants received 150 baht (approximately 4 USD) as a reimbursement for travel expenses.

Data analysis

We transcribed FGDs and KI interviews verbatim and conducted thematic analysis by coding the data in NVivo for both deductive and emergent themes. We analyzed the themes of treatment access, surveillance, and health system characteristics separately and synthesized the findings in the final analytic phase to identify the gaps and opportunities for TB control. In addition to our thematic analysis we used the data to identify where migrants and refugees could receive free TB treatment and created maps of treatment availability using Google maps software. In June 2015 NT returned to Mae

Sot, Thailand to present the maps and our preliminary findings to stakeholders as a member checking exercise to gain further input and improve the quality our findings (Guba & Lincoln, 1994). NT conducted the analysis and received support on interpreting the findings from ST, LS, FN and AF.

Results

The results from both components of the project suggest that there are both gaps and opportunities related to TB control. We describe the results around three gaps, surveillance, treatment, and funding and three opportunities, diagnostics, comprehensive care, and inter-organizational collaboration. Throughout this section we use illustrative quotes to showcase themes and ideas. We have redacted or masked all personally identifying information and use pseudonyms throughout the paper. We have chosen fictitious names that reflect the participant's gender and ethnicity.

Surveillance gaps

Based on the data from our KI interviews we identified a variety of data collection and reporting practices. The Tak PHO collects data on the number of Thai and non-Thai TB cases under its mandate from the National TB Program. The Tak PHO data is a compilation of information sent from the provincial Thai government hospitals that is integrated into a web based database and then forwarded to the National TB Program. SMRU and PUAMI collect rigorous data from their TB patients and submit reports to Tak PHO and their funders. IOM also collects data and shares this with the refugee's resettlement country. In Thailand refugees are under the jurisdiction of the Ministry of the Interior and subsequently IOM reports on its activities to this ministry as well.

We identified some gaps in the surveillance system as TB cases treated by non-governmental providers outside of the refugee camps are not included in the provincial statistics. SMRU predominantly treats migrants but also provides MDR-TB treatment to refugees. A key informant working in a local public health capacity explained that as SMRU treats cross-border patients, these numbers are not included in the provincial numbers. While PU-AMI treats refugees with TB and submits their reports to Tak PHO, it is not clear if the numbers are accounted for in the provincial statistics.

Key informants identified jurisdictional and resource barriers to integrating data on TB cases treated by non-governmental organizations (NGOs) into the provincial surveillance system. From a jurisdictional perspective, in Tak province cross-border populations that come across the border to access healthcare are not included in the general surveillance statistics. Research participants had divergent opinions about whether migrants who live in Myanmar but obtain healthcare in Tak province, Thailand should be included in the provincial and national TB statistics. Local public health officials also noted resource challenges related to integrating the TB data from different organizations into the surveillance system. A previous Tak PHO and Thailand-United States of America cooperation funded pilot project had collected TB records from all government hospitals and NGO health clinics in Tak province, however this collaboration ended and NGO data was not subsequently included in the provincial statistics.

We observed that organizations have different protocols for active screening, which could make it difficult to meaningfully combine data for surveillance purposes. For example IOM screens all refugees who are part of the resettlement scheme for TB; adults get a chest x-ray and children under the age of 15 first receive a tuberculin skin

test. As IOM screens everyone it is anticipated that their prevalence rates are higher than the other organizations that only routinely screen high-risk groups. In the refugee camp PU-AMI uses questionnaires, sputum tests, and chest x-rays to screen contact cases, new arrivals, HIV patients, healthcare workers, and patients who have diabetes or hypertension. SMRU screens healthcare workers and provides contact case tracing and screening for family members and contacts of TB patients who are in Thailand. SMRU also does active TB screening among HIV infected persons identified through a mother to child prevention program. Patients, their partners, and their children are screened for TB using a clinical questionnaire and chest x-ray for adults and a tuberculin skin test, chest x-ray and clinical screening for children less than five years old. Mae Sot Hospital (MSH) and the Tak PHO also participate in active screening programs. MSH conducts screening in migrant communities, prisons, and with Thai patients who are living with chronic disease. Tak PHO actively screens contact cases and patients living with chronic disease. Key informants working in organizations that provided TB treatment indicated that TB patients received HIV counseling and were offered HIV testing. These organizations also collected data on the number of HIV co-infections.

Treatment gaps

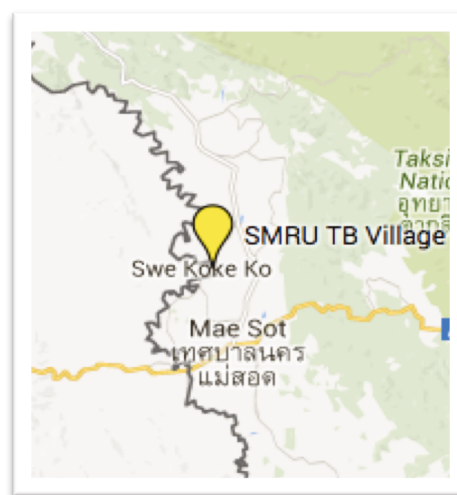
Treatment plays an important role in TB control. Our results suggest that in Tak province access to TB treatment is related to legal status (Tschirhart et al., 2016b). Migrants who have enrolled in the Thai Compulsory Migrant Health Insurance Scheme are eligible to access low cost TB treatment at the Thai government hospital. From 2011 to 2014 undocumented migrants were also able to access treatment at the Thai hospital as

Running head: ACCESS TO TUBERCULOSIS TREATMENT FOR MIGRANT

their treatment was funded by a grant from the European Union. Undocumented migrants could also receive TB treatment from SMRU and PUAMI. The mapping of treatment availability by legal status and TB subtype showed that TB treatment options for migrants become more limited as the care they need becomes more complex. Figure 3.1 shows that there are multiple locations where undocumented migrants can get TB care in the border region of Tak province, while there is only one provider for MDR-TB and TB/HIV. SMRU is the sole provider of MDR-TB treatment to undocumented migrants. SMRU also provides MDR-TB treatment to refugees who are referred from the refugee camps by PU-AMI. SMRU has two TB treatment centres along the border, one on the Thailand side and one in KoKo, Myanmar.



TB treatment



MDR-TB and TB/HIV treatment

Figure 3.1 Location of treatment availability for un-documented migrants: TB vs MDR-TB and TB/HIV. NGO clinics are marked in yellow and Thai government hospitals are marked in red. Image similar but not identical to original created using Google Maps and therefore used for illustrative purposes only.

While the focus of our research was on TB, we discovered that HIV treatment for migrants in Tak province is also limited and found that SMRU is the primary provider of TB/HIV treatment for this population. Since 2014, PUAMI has also provided TB/HIV treatment to patients regardless of status as refugees or migrants. Our team collected data from two of five district hospitals in Tak province. At the time of the study, one Thai government hospital in the border region, did not provide HIV treatment for migrants who had TB but rather only treated them for TB. A key informant from the other government hospital indicated that access to HIV treatment for migrants at their hospital was limited for two reasons. First, there is a restricted amount of funding allocated for HIV treatment for migrant patients and secondly migrants' mobility often render them ineligible for treatment as they may miss follow up appointments which could contribute to drug resistance. A physician working primarily with refugee populations expressed the challenge of mitigating drug resistance while providing HIV treatment for patients, "Because it's a long term treatment. If they are from outside, from across the border it's not easy to follow up. It can become resistant if they do not take the treatment regularly."

In some aspects having TB provides patients with preferential access to HIV treatment. A key informant working at a migrant healthcare clinic explained, "A patient with TB and HIV is luckier because SMRU after they treat the TB they have to treat for the TB and HIV too. So we can say lucky." SMRU also has a prevention of mother-to-child transmission program under which eligible women and their partners receive HIV treatment. Migrants who have HIV can also seek care at the Mae Tao Clinic, a locally run NGO, which provides HIV treatment to a limited number of patients.

Funding gaps

We identified potential funding gaps due to a lack of sustainable financing for TB treatment. For migrants with TB in Tak province, supportive care and medical treatment is closely linked to donor funding. In 2014 when we collected these data, WVT was completing a supportive care project that provided food, transportation, and daily medication to TB patients. WVT was finalizing the project and waiting for funds for its next activities. Similarly SMRU had received funding that was finishing at the end of 2014 and 2015. In addition the funding received was for a limited quota of patients. A doctor running the TB program explained the dilemma,

So we are facing a problem because our contract is through and they have additional diagnosed patients. Even for us if we diagnose a new case. I don't know how to offer the service to this person. To refer them back to Myanmar?

The key informant also indicated that they had located additional cases by using GeneXpert MTB/RIF assay, a test that can identify TB and resistance to rifampicin, one of the drugs that is commonly used for TB treatment (World Health Organization, 2014b). The GeneXpert test can provide results in less than two hours (World Health Organization, 2014b). The doctor expressed that increased case findings from the GeneXpert test further compound funding shortages. Patients also indicated concern about the funding shortage. Wiya Htoo a male MDR-TB patient who had been working as a medic at a migrant health clinic when he fell ill expressed, "I worry about my family and other people, it's hard to tell if they will have this disease. If they get it what should we do if there is no MDR-TB treatment available?"

One of the challenges associated with obtaining donor funding for Tak province noted by one of the KIs, is that as Thailand is now considered as an upper-middle income country, it may become increasingly difficult to apply for international donor funds. As treatment for migrants and refugees is predominantly provided by local and international NGOs along the Thailand-Myanmar border, there is also the potential for a gap in treatment provision when an organization ceases to operate in the border area. According to a key informant this happened when Médecins Sans Frontières (MSF) ceased its operations in Thailand in 2011.

Opportunity: Improved diagnostics

When asked if there had been any changes in methods used for TB screening in the previous two years, KI participants described an increase in the use of the GeneXpert test. One informant explained that GeneXpert was initially only used in their organization for suspected drug resistant cases but subsequently all suspected TB patients receive GeneXpert testing. At the time of our study, PUAMI, SMRU, and IOM provided GeneXpert testing to all of their TB patients. Participants explained that GeneXpert creates opportunities for enhanced TB control by assisting in the identification of individuals with drug resistant TB. A doctor running a TB program noted the benefits of GeneXpert, “Increased MDR-TB case findings in migrants and refugees in this area may be due to the use of GeneXpert test. We see cases more quickly and more and more”. However, as described above, key informants articulated that the opportunities brought about by new case findings pose a challenge for clinicians as there is limited availability of MDR-TB treatment for migrants and refugees in Tak province.

Opportunity: Comprehensive programs with good treatment adherence

While migration and patient disappearance or relocation during TB treatment poses challenges for adherence, during our analysis we found that organizations in Tak province have developed residential treatment programs and supportive care to decrease default rates among migrants. A default rate of 12.7% for non-Thai TB patients in Tak province was reported in 2012 (World Health Organization Thailand, 2013). However, SMRU, which has a residential program, had a lower default rates of 5% in 2012 and 4% in 2013. Both SMRU and PUAMI have TB villages where patients can stay during their treatment. Patients indicated that the comprehensive care, inclusive of medical treatment and supportive services, received at the TB village helped them adhere to treatment. Cho Htway, a female MDR-TB patient staying at the TB village explained, “Health care providers arrange and help us. They encourage and support us. They provide food and accommodation, free treatment and love for us”. Patients expressed strong family-like relationships with the care providers in the TB villages and explained that staff helped them adhere to treatment by offering psychological encouragement. In both residential and supportive programs, migrants and refugees play a strong role in care provision serving as medics and community health volunteers.

An added bonus of residential treatment programs, beyond treatment adherence, is that family members who accompany the patient to the clinic are also screened. A female TB clinic doctor explained that screening accompanying family members has assisted in early detection of TB among contact children which can help to prevent the negative health consequences associated with late diagnosis, specifically TB meningitis and bone TB. She described that late presentation of TB in children is common in this population,

It is very severe, if they come in with late presentation. Even though we can combat the TB but we can't solve the problem associated the neurological consequences (related to TB meningitis). And sometimes the destruction from spinal TB is really bad. They have to end up as a paraplegic or something like that.

Beyond residential programs, organizations have developed supportive programs to help ensure treatment adherence for migrant patients who were receiving treatment at the MSH. WVT organized direct observed treatment (DOT) therapy program to provide migrants with their daily TB medication at home in migrant communities surrounding Mae Sot. SMRU also had a project with MSH to visit TB patients at their residences. The funding for both projects was scheduled to end shortly after our team collected data for this project.

Opportunity: Inter-organizational collaboration

Upon examining the key informant data we found that organizations that provide TB treatment to migrants and refugees in Tak province are actively collaborating regarding patient care and overall TB control among migrant and refugee populations. These collaborations include patient referrals and the provision of supportive services. Wiya Htoo, a male migrant health worker who also became a MDR-TB patient described the inter-organizational collaboration that eased his access to care,

After I realized I had TB, the staff from my clinic made a call to the TB doctor here (at the TB residential treatment village) and then she came to pick me up

from the clinic and brought me here. Because of the easy communication I didn't have to wait long to get treatment.

Patients in the refugee camp who have MDR-TB are also referred to SMRU for treatment. Treatment providers were also collaborating with WVT, which provided supportive services such as transportation and accommodation during treatment. Maya, a female migrant health volunteer expressed how the collaboration between WVT and the local government hospital benefited patients, "If we have to go to the clinic or the hospital, World Vision will provide free treatment for us, so we don't have to worry about transportation fees and legal status". World Vision Thailand established migrant health posts run by volunteers who can record symptoms, refer potential TB cases to doctors, collect sputum and send it to the lab as well as provide transportation during treatment and DOTs.

In terms of TB control among migrant and refugee populations, organizations that provide TB treatment or supportive care and the Tak PHO belong to the TTBI. The TTBI provides a forum for organizations to share data and to develop shared strategies to treat patients and reduce number of new TB cases in the border region. As a network the TTBI also applied for and obtained funding from the European Union and the United Kingdom Department for International Development, which was then distributed to members to pay for TB treatment programs run by member organizations.

Discussion

Surveillance gaps in Tak province contribute to the invisibility of migrant TB cases. SMRU is the primary provider of TB care for migrants who have TB, TB/HIV, and

MDR-TB in Tak province. By not integrating SMRU's data into the provincial statistics, we anticipate that the burden of TB in migrant populations is under-reported. Under reporting of TB cases hampers TB control as it is difficult to identify trends and to evaluate efforts to reduce TB in migrant populations without an appropriate estimation of the actual burden. This work builds upon previous epidemiological studies, which suggest that the burden of TB is higher among migrant populations and thus an approximation of national prevalence figures from the provincial level is insufficient (Hemhongsra et al., 2008; Iemrod & Kavinum, 2015; World Health Organization Thailand, 2013).

From a health services perspective, TB treatment provision for migrants in Tak province is tenuous. At the time of our research migrants could access TB treatment from government hospitals due to donor funding. However, treatment for TB/HIV and MDR-TB, which requires more complex care, was limited to one provider. Our finding that treatment provision is closely linked to donor funding has important implications as a gap in funding could eliminate treatment options for migrants with TB/HIV and MDR-TB. The treatment availability gap for migrants would subsequently also negatively impact TB control. Research participants identified a gap in TB care provision for migrant patients in Tak province when MSF left Thailand in 2011, however our team did not find documentation that describes the impact of this gap.

The findings on the opportunities for TB control in Tak province illustrate that the foundations for further interventions are sufficiently strong. First, organizations are already collaborating by sharing data, meeting to discuss TB control and referring patients. Second, NGOs are providing migrants with comprehensive medical treatment

and supportive services, which are effective but also resource intensive. Organizations have developed a model of care where healthcare is provided in languages patients understand by Myanmar doctors, migrant and refugee medics and community health volunteers. Integrated HIV counseling, testing and treatment within these TB programs also provides an opportunity to enhance control over both diseases in the border region. Residential TB care plays an important role in the border region. Despite the disadvantages of residential treatment, specifically temporary loss of livelihood and separation from family, we found that given the mobile nature of patients, residential treatment in this context provides patients with the opportunity to receive and adhere to care. Residential treatment is especially beneficial for migrants who do not have a residence where home treatment could be provided. Third, targeted active case findings have the potential to enhance early case detection among migrants. Additionally, the use of the GeneXpert test, which can provide results within 2 hours, may lead to increased TB and MDR-TB treatment initiation in a mobile population. The increased sensitivity of GeneXpert over smear microscopy, can support the TB diagnosis of some smear negative patients which were missed by conventional microscopy (Narute, Salgia, Singhal & Kalley, 2015; Geleta et al., 2015). On the Thailand-Myanmar border, 12% of GeneXpert positive cases at SMRU are smear negative. GeneXpert's increased sensitivity over smear microscopy, may further decrease loss to follow up by avoiding additional diagnostic procedures required for clinical diagnosis of TB such as chest x-ray and antibiotic trial, which take an additional 7-10 days to conclude diagnosis. Moreover, in rapidly identifying multi-drug resistant TB, GeneXpert contributes to the early identification and treatment of MDR TB without needing to wait 4-8 weeks for a conventional culture and

drug sensitivity result. In this research context, where migrants are highly mobile and are not easily reachable for follow up, we anticipate that reduced timeframes between TB testing and results can improve the likelihood that individuals will receive their results and subsequently begin treatment. We note that this observation is specific to a mobile population. In comparison, the XTEND study, a randomized control trial control trial comparing Xpert and sputum microscopy initial testing did not find a significant difference in loss to follow up between groups, however migrants were not included in the study as participants needed to reside in the clinic area without plans to relocate for 8 months (Churchyard et al., 2015). On the Thailand-Myanmar border, where migrant populations are disproportionately burdened with MDR-TB, GeneXpert also provides clinicians with the opportunity to test for TB and begin treatment while waiting for the drug susceptibility result from growing and testing a TB culture (Hemhongsra et al., 2008).

The Thailand-Myanmar border in Tak province is a region that is undergoing a transition from a small border area to a large economic hub. With the rise of the ASEAN community has come promises of further economic integration between Myanmar and Thailand. An area close to the Thai border city of Mae Sot has been designated as a special economic zone and we anticipate the zone's new factories will increase the number of migrants coming across the border to seek work in the formal and informal sectors (Gray, 2015). As healthcare in Thailand is known regionally for its high quality, it is likely that in the future people will continue to cross the border to access healthcare in Tak province (Hemhongsra et al., 2008). In addition, if the refugee camps close, residents

who lived there may decide to continue living in Thailand and would then become part of the larger migrant population.

As migration to Tak province will likely increase, we suggest that Tak PHO explore adopting a reporting system which integrates all migrant cases regardless of their distinction as cross-border migrants who come across the border to access healthcare or migrant workers who are working and living in Thailand. The definition of migrant is fluid and we acknowledge that cross-border migrants may change their migration status to live in Thailand and migrant workers may become cross-border migrants. Furthermore, unlike refugees who are largely confined to the provinces' refugee camps, migrants are not living separately from the majority Thai population. Enumerating the burden of TB in migrant populations will make it easier to plan further interventions to address it. Our findings support the suggestion made by previous research that public health officials from Thailand and Myanmar continue to work together to strengthen data sharing on TB cases between the two countries (Kaji et al., 2015).

All stakeholders should be encouraged to continue to engage in collaborative planning around TB, TB/HIV, and MDR-TB treatment provision for migrant populations. It could be useful to explore alternative providers for MDR-TB and TB/HIV treatment provision for migrants as well as transition planning if the current single provider can no longer provide the service. MDR-TB is a serious threat to public health and is long, difficult and expensive to treat. Use of the World Health Organization newly validated short course regimen for MDR-TB treatment could assist with TB control along the Thailand-Myanmar border (World Health Organization, 2016b). The short course regimen is more cost effective than conventional treatment and reduces the time for

treatment from 18-24 months to 9-12 months, which based on a fixed drug supply could increase treatment allocation as more patients could receive treatment given the reduction in cost and duration per person. The short course regimen could also decrease loss to follow up among migrant populations. Together, increased treatment allocation and reduced loss to follow up could potentially lower TB transmission and lessen the emergence of further drug resistant strains in this community. A modeling study in Uzbekistan suggested that of the short course regimen may decrease transmission of drug resistant TB (Trauer et al., 2016). In Thailand, further discussions may be necessary to examine how MDR-TB cases in migrant populations in Thailand should be funded. The TTBI could work to address funding sustainability by investigating the possibility that the Thai government's Compulsory Migrant Health Insurance Scheme, which provides primary healthcare access, could be expanded to include MDR-TB treatment for migrants, although additional subsidies might be required to make the scheme affordable for migrants. Another possibility is for Myanmar to help fund migrants' TB treatment in Thailand through a direct fund transfer to treatment providers or through the development of a health insurance scheme for Myanmar citizens working abroad which is similar to what has been established in the Philippines (Guinto et al., 2015). Our findings support the suggestion that bi-national referral mechanisms be further developed, to allow patients to transfer between the two countries while reducing the likelihood that they will be lost to follow up (Kaji et al., 2015). This cross-border referral mechanism in addition to proper counseling may reduce concerns about drug resistance among treatment providers.

Internationally challenges with cross-border TB control have been identified along the Cameroon-Equatorial Guinea border, along the European Union's (EU) eastern border and between EU countries (Coker et al., 2004; Dara et al., 2012; Matteelli et al., 2016; Noeske et al., 2016). The cross-border work on TB control along the Thailand-Myanmar border is nascent, particularly in comparison with Europe where World Health Organization experts have developed a consensus statement on a minimum cross border TB control and care. By providing an overview of challenges and opportunities for TB control in a middle income country border region, we anticipate that our results will contribute to ongoing efforts to enhance surveillance and treatment provision (Dara et al., 2012). Health care providers and public health officials working in regions with a porous international border where availability, quality and cost of TB treatment varies significantly between nations may find this article useful as a comparator to their own experience. In analyzing their own situation, organizations may wish to consider whether all TB cases should be enumerated regardless of legal status, TB treatment, and sustainability, and what types of opportunities exist to further enhance TB control in their region.

Limitations

The socio-economic situation along the Thailand-Myanmar border is rapidly changing and one limitation of this work is that the majority of our data was collected over a single three-month period in 2014. Furthermore, due to logistical challenges we were only able to include key informants from two of the five government hospitals. As these data are qualitative we cannot generalize the results to all migrant and refugee TB

patients and health care providers along the Thailand-Myanmar border. Given the resources available for this study, we only conducted data collection on the Thailand side of the border, and as such this study does not contribute to the literature regarding TB control on the Myanmar side of the border. However, this research provides some illustrative examples of the challenges and opportunities for TB prevention and care which may be of relevance to health care providers and public health officials who are working in similar international border contexts.

Conclusion

Along the Thailand-Myanmar border in Tak province, Thailand, migrant and refugee populations are disproportionately burdened by TB. In investigating possibilities for enhanced TB control in these populations we identified surveillance, treatment, and potential funding gaps as well as opportunities in the areas of improved diagnostics, comprehensive medical and supportive care, and inter-organizational collaboration. We recognize that data sharing between countries, cross border referrals and a new MDR-TB short course regimen have the potential to positively contribute to TB control in this border region. Our findings suggest the need to enhance the surveillance system to include all migrant TB patients who seek treatment in Tak province and support efforts by stakeholders on both sides of the border to continue to share data and engage in collaborative planning on TB, TB/HIV, and MDR-TB treatment provision for migrant populations.

While the results of this study are specific to the Thailand-Myanmar border, the identified gaps and opportunities for TB control among migrant populations may be

useful for other international border regions where the availability, quality, and cost of TB treatment varies significantly between nations.

Article 4. Migrant tuberculosis patient needs and health system response along the
Thailand-Myanmar border

Naomi Tschirhart, Francois Nosten, Angel M. Foster

Author note

Naomi Tschirhart, Faculty of Health Sciences, University of Ottawa, Shoklo Malaria Research Unit, Mahidol-Oxford Tropical Medicine Research Unit, Faculty of Tropical Medicine, Mahidol University; Francois Nosten, Shoklo Malaria Research Unit, Mahidol-Oxford Tropical Medicine Research Unit, Faculty of Tropical Medicine, Mahidol University, Centre for Tropical Medicine and Global Health, Nuffield Department of Clinical Medicine, University of Oxford; Angel M. Foster, Faculty of Health Sciences, University of Ottawa.

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Abstract

This article aims to identify how the health system in Tak province, Thailand has responded to migrants' barriers to TB treatment. Our qualitatively driven multi-methods project utilized focus group discussions, key informant interviews, and a survey of community health volunteers to collect data in 2014 from multiple perspectives. Migrants identified legal status and transportation difficulties as the primary barriers to seeking TB treatment. Lack of financial resources and difficulties locating appropriate and affordable health services in other Thai provinces or across the border in Myanmar further contributed to migrants' challenges. TB care providers responded to barriers to treatment by bringing care out into the community, enhancing patient mobility, providing supportive services, and reaching out to potential patients. Interventions to improve migrant access and adherence to TB treatment necessarily extend outside of the health system and require significant resources to expand equitable access to treatment. While this research is specific to the Thailand-Myanmar border, we anticipate that the findings will contribute to broader conversations around the inputs that are necessary to address disparities and inequities. Our study suggests that migrants need to be provided with resources that help stabilize their financial situation and overcome difficulties associated with their legal status in order to access and continue TB treatment.

Introduction

Tuberculosis (TB) disproportionately impacts vulnerable populations. Individuals who experience poverty face an embedded disadvantage as being poor is associated with a higher risk of TB infection, active disease, delayed diagnosis, poor adherence, and

fatality (Lönnroth et al., 2014; Noyes and Popay, 2007). Concerns about lost earnings and transportation costs influence poorer patients' decisions to seek treatment (Noyes and Popay, 2007). Socio-economic status also influences adherence to TB treatment, as therapy is lengthy and patients may experience a reduction in income (Mauch et al., 2013; Naidoo et al., 2013; Paz-Soldán et al., 2013; Richter et al., 2014). Migrant populations experience this tension between their financial obligations and a need to continue TB treatment as well as additional difficulties related to legal and registration status (Bele et al., 2014; Shringarpure et al., 2016; Xu et al., 2009). The Stop TB Partnership's Global Plan to end TB identifies migrants as a priority group that has limited access to TB treatment (Stop TB Partnership, 2015). In recognition of the specific challenges migrants face when accessing healthcare, a global consultation identified the importance of migrant sensitive health systems that "consciously and systematically incorporate the needs of migrants into health financing, policy, planning implementation and evaluation" (World Health Organization, 2010, p.61). Delivery of migrant sensitive care is enhanced through interpretation services, culturally informed care and programs, and cultural support personnel such as community health workers (World Health Organization, 2010). To date, literature on how providers respond to TB patients' non-medical needs remains limited and little is known about how health systems respond to migrants' needs, in particular (Noyes and Popay, 2007; Richter et al., 2014).

The Thailand-Myanmar border is a region of increasing geopolitical importance. Separated by the Moei river, Tak province in western Thailand and Kayin state in eastern Myanmar share a distinctive mountainous topography and a long history of transnational migration. Recent peace agreements in Myanmar signaled the end of a decades-long

conflict that had sent thousands of refugees across the border to Thailand. Improved political stability has spurred economic development and the Thai border town of Mae Sot is emerging as a significant economic centre. An estimated 300,000 registered migrants and 90,000 refugees live in Tak province; cross-border migrants live in Myanmar and traverse the border to seek care (Hemhongsai et al., 2008; Iemrod and Kavinum, 2015). Along the border, healthcare is provided to migrants by Thai government hospitals and non-governmental organizations (NGOs). Migrants typically make less than the national daily minimum wage of 300 baht (USD 8) and individuals who lack the necessary documentation to remain legally in Thailand face difficulties travelling around the province and must try to avoid the police checkpoints which dot the landscape (Tschirhart et al., 2016a, 2016b). Refugee and migrant populations living in Tak province are disproportionately burdened by TB (Hemhongsai et al., 2008; Iemrod and Kavinum, 2015). While TB treatment for undocumented migrants is not covered under Thailand's universal healthcare program, Thai government hospitals may give TB treatment on a case-by-case basis depending on funding. In 2014, a grant from the United Kingdom's Department for International Development and the European Union provided funding for undocumented migrants' TB treatment at five Thai government hospitals close to the border.

In this region NGOs established specific TB programs to provide care for migrants who were not eligible for free healthcare from the Thai government hospitals or needed additional supportive services (Tschirhart et al., 2016a, 2016b, 2017). World Vision Thailand (WVT) and the Shoklo Malaria Research Unit (SMRU) run community-based TB programs. WVT's TB program operates in partnership with Mae Sot Hospital,

the district government hospital, and is run through community health posts in migrant communities around Mae Sot. Community health volunteers (CHVs) provide basic health services and help arrange transport for patients who need to go to the hospital. The tradition of CHVs, individuals who provide basic health care, is well established among both Thai populations and migrant populations on both sides of the Thailand-Myanmar border (Kowitt et al., 2015; Lee et al., 2009). WVT's program provides care to foreign labour migrants who are residing in the greater Mae Sot area. Conversely, SMRU's TB program provides care to a wider population including refugees, cross-border migrants, and migrants living in Thailand. SMRU has developed a residential program where patients come to stay at the treatment centre. The SMRU TB village sits on a hill surrounded by agricultural fields just outside of Wang Pha village on the Thai side of the Thailand-Myanmar border. Rows of one-room dwellings accommodate patients and accompanying family members are housed separately. Patients are provided shelter, medication, and food free-of-charge.

In addition to WVT and SMRU, Mae Tao Clinic (MTC) and Première Urgence - Aide Médicale Internationale (PU-AMI) also contribute to TB control among migrants. MTC, a well-known clinic that provides healthcare for migrants along the Thailand-Myanmar border, assists in the detection of a large number of TB cases and refers patients to SMRU for TB treatment. PU-AMI runs a TB program in the refugee camp that is predominantly for refugees but also treats migrants who have gained access to the camp. As mobility in and out of the refugee camp is severely restricted, migrants who gain access to the camp often have a family connection and permission to enter which allows them to seek TB care from PU-AMI.

Our research project aimed to investigate access to TB treatment for migrants and refugees, TB surveillance, and health systems response. We have published our findings on treatment accessibility, surveillance, and TB control elsewhere (Tschirhart et al., 2016a, 2016b, 2017). In this article we address the research question: how have community and non-governmental healthcare providers responded to treatment barriers? Drawing from focus group discussions (FGDs), key informant (KI) interviews and a CHV survey, we identify how the health system, inclusive of CHVs, medics, doctors, and program administrators, has responded to barriers to TB treatment experienced by migrants in Tak province, Thailand. We define responsive actions as initiatives undertaken to address migrants' needs. We examine responses by NGO TB programs and CHVs, which seek to improve migrants' access and adherence to TB treatment.

Materials and Methods

Data collection

We conducted fieldwork for this research project in Tak province Thailand from July to October, 2014. Our multi-methods project utilized focus group discussions, key informant interviews and a survey of community health volunteers to explore access to TB treatment from multiple perspectives. We have described our FGD and KI methodology in detail in previous articles (Tschirhart et al., 2016a, 2016b, 2017).

Focus group discussions

With the assistance of Burmese and Karen language interpreters we conducted 11 FGDs with migrant and refugee TB, multidrug-resistant tuberculosis (MDR-TB), and TB-HIV patients to solicit information on barriers to treatment. Patient participants were undergoing treatment at three different treatment centers, namely a Thai government hospital, a clinic in the refugee camp and a TB village that provides care to migrants. We also held four FGDs with community health volunteers who were associated with a TB program that provides supportive care.

Key informant interviews

We interviewed 13 KIs who were working with different organizations as TB treatment providers, program administrators, and public health officials. In interviewing KIs we sought to gain insight into their experience and perceptions based on their work in TB control (Kelly, Susan E., 2010). Our interview guide explored perceived barriers to treatment for migrants and refugees as well as responsive actions. We asked KIs to identify changes that had been implemented in the previous two years as well as responsive actions aimed to improve treatment access.

Community health volunteer survey

In an effort to understand better CHVs' contribution to TB control in Tak province we conducted a baseline survey of volunteers (n=101) affiliated with a TB program run by WVT. Our sample represents approximately half of the total number of CHVs associated with this program. TB program staff recruited CHVs in the peri-urban

Mae Sot area. To be eligible for the survey CHVs had to be currently affiliated with a community health program in Tak province, 20 years of age or older, sufficiently fluent in Thai, English, Karen or Burmese to complete the survey, affiliated with a TB program, and willing to provide consent to participate. WVT staff collected data and read the survey to volunteers and wrote down the answers. Survey questions elicited information on CHVs' contributions to TB treatment, referrals, and surveillance. The questionnaire is available upon request.

Data analysis

We transcribed and translated all of the audio files from the FGDs and KI interviews into English and used NVivo 11 software to manage the data. We employed a hybrid deductive and inductive approach to thematic analysis and coded the data for pre-determined themes as well as those which were emergent and data driven (Boyatzis, 1998). Our high level deductive themes of treatment barriers and responsive actions are integral to the study's research aims; we included these in the FGD and KI interview guides. We simultaneously coded the data for themes, distinct explanatory constructs, and for codes, smaller units of analysis which help to explain the phenomenon (Boyatzis, 1998; Guest et al., 2012). To further investigate perceived barriers to treatment we separated the perceptions of migrants, refugees, and KIs and explored the overlap and concordance (Tschirhart et al., 2016b). After discovering that migrants reported more difficulties accessing treatment than refugees, we mapped responsive actions onto migrants' barriers to care.

To analyze the CHV survey data we manually entered the survey responses into Excel and then conducted descriptive statistical analyses using SPSS software. We used Fisher's exact test to examine the relationship between categorical variables and look for statistical significance. However given the baseline nature of this survey and the large number of categorical variables, we did not find any meaningful statistical relationships. Thus, we report the descriptive frequencies in this article.

Ethics

All participants provided consent prior to participating. We received ethics approval for this study from the Health Sciences and Sciences Research Ethics Board at the University of Ottawa (File #H02-14-08), the Oxford Tropical Research Ethics Committee at the University of Oxford (538-14), and the Tak Provincial Public Health Office (TK 1/2557).

Results

Barriers to treatment

Migrants identified legal status and transportation difficulties associated with not having the appropriate documentation as the primary barriers to seeking TB treatment (Tschirhart et al., 2016b). Lack of financial resources, in addition to difficulties locating appropriate and affordable health services in other provinces of Thailand and across the border in Myanmar, contributed to the challenges faced by migrants with TB (Tschirhart et al., 2016a). In a previous article we reported the barriers and enabling factors for migrants and refugees seeking TB treatment (see Table 2, Tschirhart et al., 2016b). Here

we have provided a list of migrants' major barriers to treatment along with the responsive actions in Table 4.1. In our KI and FGD data we identified responsive actions at the individual and programmatic levels that sought to improve migrants' access and adherence to TB treatment.

Table 4.1 Barriers for migrants seeking TB treatment and responsive actions

Thematic Domain	Barriers	Responsive actions	Actor
Financial	Family/work responsibilities	Accommodation for family members at the TB village	SMRU
		Outpatient care	WVT and SMRU
	Money problems	Community fund	Migrant community members
		Financial support	Individual health care providers
		Food and accommodation	SMRU
Housing	Accommodation at the TB village	SMRU	
TB Health services	Language	Provide free TB care in languages migrants understand	SMRU, WVT in collaboration with Mae Sot Hospital and PU-AMI
	Treatment cost		
	Services not available		
	Time to diagnosis	Improved diagnostics	SMRU
	Duration	Outpatient care	WVT/SMRU
	HIV co-infection and stigma	Expand treatment eligibility to include family members	SMRU
Transport	Travel restrictions	Deliver medication	SMRU
	Police/documents	Provide travel documents	SMRU
	Travel cost	Organize transport	SMRU and WVT
Legal status	Undocumented	Policy change on migrant worker registration and healthcare scheme enrollment	National Government of Thailand
		Provide travel documents	SMRU
Patient beliefs and behaviours	Delayed care seeking	Increased screening	WVT and SMRU
	Limited knowledge of TB and health system	Information dissemination by health volunteers	WVT
		Links with migrant health clinics	SMRU
		Counseling	SMRU
	Mobility	Counseling	SMRU and WVT
Contract		WVT	
Psychosocial support	No caregiver	Psychosocial activities	SMRU
		Encouragement	WVT Community health volunteers

Responsive actions

Based on both the FGDs and the KIs, we identified two organizations that had adapted their services and service delivery in response to difficulties experienced by migrant patients. WVT and SMRU responded to migrants' needs by simultaneously bringing care out into the community, enhancing patient mobility, providing supportive services, and reaching out to potential patients.

Community-based care delivery

Migrants who participated in our research project were primarily daily waged laborers. In seeking TB treatment they lost income for the days they were unable to work. Our participants, many of whom had minimal savings to offset the impact of lost wages, described the difficulty of balancing their own need for TB care with their familial financial responsibilities. A cross-border male migrant TB patient explained, "In my house I'm the main provider so it's a problem for my family when I'm away for treatment. I worry for my family. Even if it's not easy, I can't do anything about it because I was sick and needed to seek treatment in order to get well."

WVT and SMRU have responded to migrant patients' financial challenges by adapting service delivery to bring TB treatment out of the clinic and into the community. In the WVT program, patients initially receive TB treatment from a doctor at the Thai government hospital and subsequently WVT CHVs provide TB medication to the patient through the community health posts. A volunteer described,

It's ok because the volunteer health worker will come and give medication at your home every day and you can still continue your work. Usually the volunteer

health worker also has their own work so they'll give one month of medication at the same time or sometimes for one week because they can't come every day.

World Vision makes it easy for us, they bring medication at home so we don't have to go to another hospital or clinic like in the past.

In response to patients' need to support their families, SMRU began offering community-based outpatient care to individuals who had successfully completed two months of treatment at the TB village and had shown good adherence. A key informant explained this rationale behind this change,

To promote adherence, before we persuaded all of the patients to stay in our TB village before we completed treatment. But now we learned from them that they have a really hard life and they have families that rely on them. If we keep them over here, if we are very strict, they will run away. So some of them who have finished two months of treatment and have shown good adherence, if they are willing and fit to go, we let them go. But we have more logistical work to do to provide transport for their follow-up appointment or to follow-up with Mae Sot Hospital or Mae Tao Clinic for their drug supply.

SMRU also has health workers and home visitors working in the community who can help to follow up with patients and provide medication in circumstances where migrants are unable to travel for follow-up treatment. In addition, SMRU opened another TB village just across the border from Tak province in Koko, Myanmar where migrants can seek care without having to cross the border into Thailand.

Enhancing patient mobility

As we have detailed elsewhere patients indicated that their ability to travel was closely related to their legal status and whether they had the correct documentation required to travel freely within Tak province (Tschirhart et al., 2016a, 2016b). Key informants who were working as health care providers also acknowledged migrants' mobility challenges (Tschirhart et al., 2016b). WVT and SMRU responded by providing transportation to help patients reach treatment. A female migrant patient with MDR-TB described, "I have no legal status so whenever I pass the check point then I had to pay the police. But now I don't have to pay and be afraid of the police because now SMRU arranges everything for me."

To further enhance patient mobility, patients are provided with a treatment card which they can attempt to use to negotiate with law enforcement as evidence of a legitimate reason for travel. A key informant explained, "We try to negotiate through our logistics team with local authorities, to explain that we are providing treatment like this, so when he comes to collect the drugs please let him go if he can show this card. Meaning that they have a treatment card and adherence check documentation."

Providing supportive services

Migrant TB patients who participated in our study had a limited amount of available financial resources to offset the indirect costs associated with TB treatment (Tschirhart et al., 2016a, 2016b). Participants indicated that food, accommodation, and psychosocial support services helped them to access and continue treatment (Tschirhart et al., 2016b). Through residential care at the SMRU TB village, migrants receive meals

and housing for themselves and their family members. A key informant explains the decision to extend housing to family members, “For male TB patients, not being able to earn money to provide for their family is a big challenge. This is especially true for migrants. So that’s why we have to keep their family members along with the patient at the clinic.” While participants did not receive cash incentives for completing treatment, several patients indicated that care providers gave them pocket money to assist with their expenses. Our understanding is that these funds came from the care providers themselves and not the program.

TB treatment can be lengthy and isolating. Treatment providers responded to patients’ psychosocial needs by providing activities and personalized counseling. At the SMRU TB village, staff set up handicrafts and gardening activities to boost patients’ spirits. WVT volunteers described “encouraging patients not to give up” as part of their role. Patients explained that in some cases they were separated from their families during treatment and that they really valued the encouragement provided by health care providers. Treatment providers emphasized the importance of providing personalized counseling and described talking at length with patients about TB progression and the importance of adhering to treatment. A TB physician described a typical conversation, “You need to take treatment. It might take six months. So where would you like to get the treatment? Wherever you go the treatment is free of charge. The main thing is to select a location where you can get treatment until the end of the period.”

Providers explained that counseling around adherence was linked to concerns that high mobility among migrants might lead to treatment default and subsequent drug resistance. We found that mobility itself is an indirect barrier as it limits patients’

eligibility for care. Health care providers responded to mobility-related apprehensions by asking patients to commit to completing treatment and counseling individuals on available treatment locations. At the time we collected data, cross-border TB referral was being developed. A TB clinician expressed, “So once it’s diagnosed we want to at least reach them for counseling. Where do they want to take treatment? Myanmar or where?”

Reaching out to potential patients

Migrant TB patients described delaying seeking treatment until they could no longer work. Both WVT and SMRU TB programs incorporated initiatives designed to reach out in search of potential TB patients.

In the two years prior to our data collection, WVT and SMRU introduced enhanced TB screening programs. WVT changed from screening symptomatic cases to a community wide screening protocol. SMRU initiated screening of family contacts who were living in Thailand, in addition to members who accompanied the patient to the clinic. Enhanced TB screening can help identify asymptomatic TB cases and provide individuals with the opportunity to initiate early treatment and to avoid the negative consequences associated with late diagnosis.

In efforts to reach more patients, SMRU also set up a partnership with a popular migrant health centre, the Mae Tao Clinic. SMRU TB doctors travel to MTC to diagnose potential TB patients who are then referred to the TB village. Additionally, SMRU also began offering HIV treatment to immediate family members of TB-HIV patients, who would otherwise be ineligible for free HIV treatment in the region. This programmatic change was made principally to prevent domestic abuse experienced by women who disclosed their HIV status to their husband.

Additional responsive actors

While we profile two TB treatment programs in this article, it is important to note that there are other actors who have responded to migrants' barriers to TB treatment. The first are migrants themselves. CHVs described how they had developed a community fund to collect money for transportation. This was initially a WVT project that is now run directly by the migrants. A volunteer explained, "We organized a volunteer group in our community and collect 20 baht/month (USD 0.60) from each member and save it to help our migrant workers when needed".

Another volunteer detailed the purpose of these actions,

Our main point is to help our Burmese people to unite together and lift them up.

Even though we are in another country, we don't want people to look down on us,

on our people. We plan and prepare for our people in case they need help. If they

are sick and have to go to the hospital and they don't have money for

transportation fees then here is the money. We planned and saved it in advance.

But we can't pay for the treatment fees, we can just help with anything we can afford.

CHV survey

CHVs affiliated with the WVT TB program are foreign labour migrants living at the edge of the urban core in neighborhoods that are densely populated by migrants. In each community, volunteers run a local health post where they provide health information, collect sputum for TB testing and help link migrants to TB care. Our survey with migrant community health volunteers enabled us to document their contributions to TB treatment, referral and surveillance. Table 4.2 provides information on the sample's

demographic characteristics. Participants were predominantly female (70%) with a majority aged 30-49 (62%). Another study from two Thai border provinces similarly found that most (56.9%) of the migrant volunteers were women (Sirilak et al., 2013). In our sample, most CHVs spoke Burmese, self-identified as documented migrants (60%) and had been working as a CHV for two or more years (55%).

Table 4.2 Community health volunteer demographic characteristics

	N (%)
Total	101 (100%)
Demographic characteristics	
<i>Gender</i>	
Male	29 (29%)
Female	70 (70%)
Missing	2 (2%)
<i>Age</i>	
< 20-29	22 (22%)
30-49	62 (61%)
50>59	17 (17%)
<i>Legal Status</i>	
Undocumented migrant	30 (30%)
Documented migrant	61 (60%)
Thai citizen	1 (1%)
Prefer not to answer	3 (3%)
Missing	6 (6%)
<i>Languages spoken **</i>	
Karen	17
Burmese	94
Thai	13
Other	2
Missing	3
<i>Length of time as a community health volunteer</i>	
< 6 months <12 months	20 (20%)
1 < 2 years	23 (23%)
2 or more years	55 (54%)
Missing	3 (3%)

**Percentages are not reported for multiple answer questions

In the last 12 months prior to our survey in 2014, most CHVs had provided TB treatment (64%) and supervised Directly observed treatment (DOT) (57%). A smaller percentage of respondents provided TB/HIV treatment (20%) and TB/HIV DOT (22%) in the same period. Few participants had provided HIV treatment (16%), MDR-TB treatment (10%) or supervised MDR-TB DOT (8%). Table 4.3 details CHV contributions to treatment and surveillance.

To examine CHVs contribution to the identification of new TB and HIV cases we asked how often they had referred suspected cases for testing in the previous year. The majority of the respondents referred suspected TB patients for testing most of the time (28%) or always (45%) and indicated that they would notify someone if they found a new suspected case of TB (87%). Most respondents (56 individuals) would notify the NGO running the TB program. Referral of TB patients for HIV testing was more evenly distributed between categories with never (30%), rarely (2%), sometimes (28%), most of the time (21%) and always (20%). In regard to surveillance in the previous year, 45% of participants had collected data on infectious disease in their catchment area.

Table 4.3 Community health volunteer contribution to TB treatment and surveillance

	N (%)
Total	101 (100%)
Contribution to treatment	
<i>Provided TB treatment in last 12 months</i>	65 (64%)
<i>Supervised DOT in last 12 months</i>	58 (57%)
Missing	1 (1%)
<i>Provided MDR-TB treatment in last 12 months</i>	10 (10%)
<i>Provided TB/HIV treatment in the last 12 months</i>	20 (20%)
<i>Referral TB patients for HIV test (last 12 months)</i>	
Never	30 (30%)
Rarely	2 (2%)
Sometimes	28 (28%)
Most of the time	21 (21%)
Always	20 (20%)
<i>Referred TB patients for HIV testing to **</i>	
Community health worker	24
World Vision	35
Mae Tao clinic	8
Hospital	8
Other	3
Not relevant	30
Missing	2
<i>Referral of suspected TB patients for testing (last 12 months)</i>	
Never	3 (3%)
Rarely	1 (1%)
Sometimes	22 (22%)
Most of the time	28 (28%)
Always	45 (45%)
Missing	2 (2%)
Contribution to Surveillance	
<i>Notification of new suspected TB case</i>	88 (87%)
Missing	1 (1%)
<i>Organization notified re: suspected TB case</i>	
Community health worker	26
Thai public health clinic	1
World Vision	56
Other	6
Not relevant	12
Missing	7
<i>Collected data on infectious disease in the last 12 months</i>	45 (45%)
Missing	1 (1%)

Discussion

Studies on the support provided to TB patients are limited (Noyes & Popay, 2007). Along the Thailand-Myanmar border, TB treatment is standardized. Thai government hospitals follow national protocols and SMRU utilizes World Health Organization (WHO) recommendations for TB care. Success rates are close to global standards. SMRU's TB treatment success rates for migrant patients in 2013 and 2014, 82%, were close to the WHO 85% success target rate. (Tak Tuberculosis Border Initiative, 2015). Our results suggest that in this context two NGOs have developed responsive and flexible programs that are adapted to suit migrant patient's needs. For example, after completing an initial residential period, migrants who are living in the Mae Sot area can choose community-based TB care or residential care. A strength of these programs is that they help migrants overcome mobility challenges related to their legal status by simultaneously bringing patients into clinical spaces to receive care from physicians and also taking TB care out into the community. By providing free treatment both programs address some of the catastrophic patient costs associated with TB treatment (Munro et al., 2007; Rasanathan et al., 2011). Giving patients the opportunity to continue working and receive care at home, or stay in a residential facility where food and accommodation are provided further diminishes their out of pocket expenditures. These programs have incorporated the essence of migrant sensitive health service delivery through the provision of care in languages patients speak by community health workers and volunteers who are knowledgeable about the local culture.

In examining the actors who responded to address barriers to treatment, we found that migrants themselves were often frontline TB treatment providers. While both of the TB programs that we profile in this article were overseen by NGOs, TB care was provided by Thai and Burmese physicians with the assistance of migrant CHVs and medics. We perceive that medics' and volunteers' identities as migrants may further enhance their desire to respond to patient needs as a means to improve the lives of migrants living in Thailand. The way that CHVs framed their rationale for volunteering may be related to the way they see themselves, as members of a minority group in a foreign country where they need to work together in solidarity. Our survey did not collect information on reasons for volunteering but a CHV survey with a similar migrant population found that 98.1% believed that volunteer work assisted members of their ethnic group (Sirilak et al., 2013). This model of care, where migrants are embedded in treatment programs as medics and volunteers, is not limited to TB programs but is commonly used by numerous organizations that provide healthcare to migrant populations along the border. We perceive that this model is in itself responsive and that further research on health systems response for other health conditions is warranted.

While we cannot quantify the impact of CHV work on TB control in Tak province, their contribution should not be ignored. Delayed care seeking is a barrier to TB treatment among migrant populations in this region (Tschirhart, et al., 2016b). We found that 87% of CHV would notify someone if they found a suspected TB case, and we anticipate that this could lead to earlier access to treatment and a reduction of co-morbidities associated with delayed care seeking. In addition, CHVs' provision of TB treatment in the community is likely to have positive economic spin-offs as migrants can

receive care while continuing to work. Despite the potential contribution of CHVs to TB control, we anticipate that additional research is necessary to further explore migrants' motivations for volunteering and the long-term sustainability of a volunteer run TB initiative. As volunteers CHVs are not paid. Identifying ways to compensate these individuals for their important work in supporting TB patients, identifying new cases, and contributing to the program appears warranted.

From a policy and practitioner perspective it is important to note that many of the barriers that migrants reported exist outside of the health care system. Legal status, transportation and patient financial difficulties do not originate in the health system but are related to the social, legal and economic environments where migrants live (Tschirhart et al., 2016b). In responding to patient barriers to treatment, through the provision of accommodation, food and transport treatment providers are intervening to address the underlying social determinants of health. Health system actors described interceding with actions to improve migrants' living conditions for the express purpose of improving access to TB treatment and adherence. This type of engagement was described as necessary and may point to a need for future inter-sectoral action to address TB in migrant populations along the Thailand-Myanmar border.

Our study found that significant financial and non-financial supports are necessary to help improve migrants' access and adherence to TB treatment. While this research is specific to the Thailand-Myanmar border, our results engage with broader issues of health equity and the inputs that are necessary to close the gap (Marmot, 2015). Our results suggest that migrants need to be provided with resources that help stabilize their financial situation and overcome difficulties associated with their legal status in

order to access and continue TB treatment. We agree with Richter et al. (2014) that cost-effectiveness is an important topic for future research as additional information is needed to improve the evidence base for policy decision-making.

Recent discussions on TB control among migrant populations in Europe have emphasized the potential benefits of pre-screening migrants from high burden countries (Aldridge et al., 2016). However, we agree with van der Werf and Kramz (2016) that relying predominantly on pre-screening would overlook the undocumented migrants who arrive in their destination country without the appropriate visa. Based on our findings along the Thailand-Myanmar border we recommend countries consider how to make their TB screening programs responsive to migrants needs. Provision of post-arrival screening free of charge to undocumented migrants, as is done in Israel, may be a beginning but national TB programs may also wish consider how they can create programs that allow migrants to receive screening without repercussion regardless of their legal status (Chemtob, Mor, & Grotto, 2015). In parallel to screening programs, we believe that broader national TB program migrant strategies should consider how they can incorporate migrants as health workers and liaisons between the public health department and the community.

When we were collecting the data for this project the national Thai government was implementing changes to the community migrant health insurance scheme. Previously, employers had to register migrants for this benefit but as of August 2014 migrants could register themselves and pay directly into this scheme (Guinto et al., 2015; Prevention of HIV/AIDS Among Migrant Workers in Thailand, 2014). We interpret this policy measure as an example of responsiveness by the Thai government to the general

difficulties that migrants have accessing healthcare through the public system in Thailand. However, we anticipate that many migrants cannot afford to buy into the migrant health insurance scheme.

In conclusion, we found two NGO TB programs in Tak province that are highly responsive to the challenges migrants face when seeking treatment. Their responses necessarily extend beyond the health system and address the social, legal and economic environments where migrants live. This study from the Thailand-Myanmar border offers valuable lessons to policy makers and practitioners working with migrants in other jurisdictions. Organizations may benefit from identifying treatment barriers in consultation with patients and responding with initiatives that stabilize migrants' financial situation and address obstacles associated with their legal status.

Limitations

It is important to note that we did not collect information on the cost or effectiveness of these supportive measures. We collected our data over a three-month period in 2014 and acknowledge that TB control and migrant health initiatives continue to evolve. As such, the results of our study should be considered within this temporal period. Our data, given its qualitative nature, cannot be generalized to the experiences of all migrants along the Thailand-Myanmar border. However, we anticipate that the themes generated by this work can contribute to the dialogue on migration and health system response in Southeast Asia and other regions such as Europe that are developing strategies to address TB control among migrants.

DISCUSSION

The primary aim of this thesis project was to examine TB treatment access for migrants and refugees in Tak province, Thailand. To study TB control from a wider perspective, we also sought to understand how migrant and refugee cases are enumerated in the public health surveillance system and explored treatment providers' responsiveness to treatment barriers.

Summary of the main findings

The first article, "Migrant and refugee patient perspectives on travel and tuberculosis along the Thailand-Myanmar border", on TB and travel sets the context for the thesis. We found that:

- Migrants are travelling long distances with active TB;
- Travel, while arduous, is an adaptive strategy used by migrants to seek TB treatment; and
- There is a wide catchment area for migrant patients who seek TB treatment in Tak province.

In the second article, "Access to free or low-cost Tuberculosis treatment for migrants and refugees along the Thailand-Myanmar border in Tak province, Thailand", we delve into treatment access considerations. We observed that:

- Migrants have more barriers to accessing TB treatment in Tak province than refugees;
- Legal status influences migrants' eligibility for treatment and ability to travel; and

- Migrant patients expressed that availability of TB, TB/HIV, and MDR-TB treatment in Tak province as well as additional supports enabled them to access and adhere to TB treatment.

The third article, “Treating the invisible: Gaps and opportunities for enhanced TB control along the Thailand-Myanmar border”, shifts to explore gaps and opportunities for TB control. We discovered that:

- TB/HIV and MDR-TB treatment options for migrants in Tak province are limited and are heavily reliant on donor funding;
- Based on our data, Migrant and refugee TB cases appear to be under reported in the public health surveillance system; and
- Improved diagnostics, comprehensive care and inter-organizational collaboration provide opportunities for enhanced TB control.

In the fourth article, “Migrant tuberculosis patient needs and health system response along the Thailand-Myanmar border”, we identify how organizations have responded to migrant’s barriers to treatment. We found that:

- Two NGOs have developed programs that are responsive to migrant barriers to treatment. These programs bring care into the community, enhance mobility, provide supportive services and reach out to potential patients; and
- Interventions to improve treatment access and adherence to TB treatment necessarily extend outside of the healthcare system and address the social determinants of health.

Unexpected findings

During the summer of 2013, prior to defending the thesis proposal and entering the field, I had an opportunity to visit Mae Sot, Thailand and to spend a couple of days with an SMRU TB doctor. This visit, in addition to a literature review helped to provide context on migrant healthcare in the Thailand-Myanmar border region and to identify some well-known difficulties such as legal status, transportation and lack of financial resources.

Once I conducted the fieldwork and the subsequent data analysis three findings emerged which were unexpected. The first two, patients travelling long distances and under reporting of TB cases are main findings that are elaborated in the articles. As previously discussed we suspect that long distance travel and the respective large catchment area are related to difficulties accessing free or low-cost treatment in Bangkok, Thailand or inside Myanmar. While Hemhongsai et al. (2008) in their report on a surveillance pilot project had indicated that TB records were not previously systematically collected and integrated into the public health surveillance system, before the fieldwork we didn't have any information that suggested that the pilot project was discontinued and records were no longer being collected from NGOs.

A third unexpected finding was a narrative on the characteristics of a perfect patient. This theme was brought forward by some treatment providers and was not fully described in the thesis article as I perceive that while interesting this theme sits on the boundary of the thesis objectives. Providers described "good" patients as individuals who were psychologically strong and would adhere to treatment. On the other side of the dichotomy were patients who are mobile, as mobility itself was considered by some

providers as a barrier to treatment. While concerns about mobility and exclusionary criteria are grounded in scientific evidence on the dangers of loss to follow-up and the subsequent potential of drug resistance, I think that there may be a need to further elicit information on this domain. Based on our research it appears that at government hospitals, migrants may not be eligible for some treatments like HIV/AIDS treatment due to concerns about mobility and the potential that they will default. Limited accessibility to HIV/AIDS treatment can cause difficulties for migrants with TB/HIV. I am concerned that a narrative, which presents migrants as potentially difficult patients who may contribute to drug resistance, could be detrimental for TB control in Tak province.

Researcher positionality and reflexivity

As a qualitative researcher I believe that it is important to reflect on my own identities and my position in relation to the research project. Following Kimberle Crenshaw's (1989) perspective that individual identities are intersectional, I identify as a white, middle-class woman from rural Atlantic Canada. Acknowledging that individuals have multiple overlapping positions, I describe here how my positions as a Canadian, feminist, insider/outsider and white academic influenced our study. As a Canadian I have an entrenched belief that people, regardless of citizenship, should have access to healthcare. This belief influenced the research question and the focus on analyzing the pathways individuals used to get care. At the onset of the project, in addition to belief in healthcare for all, I was also interested in examining how gender influenced access based on my own personal feminist quest for equality. Once I entered the field, I discovered that gendered identities influence care predominantly for men who are family

breadwinners. Women did not report gendered barriers to care. This finding surprised me and challenged my pre-conceived notions of predominant patriarchal power relations.

The Thailand-Myanmar border where I undertook the research is a cross-cultural environment and I had predominantly Thai, Burmese, and Karen participants along with a few foreigners. In this space my positionality slid on a scale from hybrid insider/outsider to outsider (Merriam et al., 2001). I had previously volunteered many years ago with a Karen minority group NGO and had some understanding of the political context along the Thailand-Myanmar border. I also spent two years at Chiang Mai University during my undergraduate studies and developed some conversational Thai language skills. My knowledge of Thai language and my extended Thai family helped me to position myself as an insider/outsider and assisted me to build relationships to enter the field. Yet the majority of the research happened in Burmese and Karen languages, and thus in this space I anticipate that as an outsider I may have missed some of the nuanced meaning. In efforts to lessen the impact of my outsider status, I debriefed after each of the focus group with Tabitha our Karen interpreter and research assistant (Miles et al., 2014). My discussions with Tabitha helped me to put the data in context.

As a white academic, my race and the privilege associated with academia influenced both the data collection and analysis. Unlike many of my research participants I was able to travel around the province with minimal questions from the police. I am also aware of the privilege associated with being able to create a space for discussion about access to healthcare for migrants. Academics of European ancestry conducting social science research in South-east Asia must be mindful of what Edward Said (1979) coined as “Orientalism” which is essentially the European construction of Asian identity

as the exotic and lesser other. Examples of Orientalism can be found in fictional writing about Burma such as *Burmese Days* written by George Orwell (Orwell, 1974). In keeping this in mind during the data collection and analysis, I viewed participants as actors in their own right. I purposely looked closely to identify examples of migrants' agency to address their challenges and improve their own lives. I anticipate that this viewpoint has shaped the findings. I am also aware of my position as an aspiring academic and the associated positionality as an expert. To mediate my position as an expert I purposely tried to keep the findings close to data and used direct quotes to highlight participants' voice. While the primary purpose of data collection was to collect information about participants' lived experience, at the end of each interview or FGD I gave participants the opportunity to ask me questions. Miles, Huberman and Saldaña (2014) suggest that researchers consider their relationship with participants. I believe that offering to answer participants' questions contributed to our relationship by embodying honesty and developing trust (Miles et al., 2014).

Research contributions

I am confident that this qualitatively driven research project is credible and trustworthy. I believe that collecting data from multiple perspectives, including clinicians, patients and volunteers, enhanced the credibility and trustworthiness of our research. As this project is grounded in the experience of patients and health service providers, I anticipate that the results from this research will have implications for research, theory, practice, and policy.

Research

The pertinence of the research results should be considered both for their contribution to the state of knowledge along the Thailand-Myanmar border and to the larger international body of literature on TB and migration.

Literature on TB in migrant populations along the Thailand-Myanmar border remains sparse. I believe that this thesis addresses this gap by bringing forward articles which put forward the patient perspective as a complement to previous epidemiological studies (Aeumrod, 2008; Hemhongsra et al., 2008; Iemrod & Kavinum, 2015; Minetti et al., 2010). While the challenges faced by migrant patients accessing TB treatment appear to be well understood by local healthcare providers, this is the first time they are being documented in the academic literature.

Our results on the barriers and enabling factors for migrants seeking TB treatment complement the wider literature on TB and migration which suggests that legal status and fear of authorities, personal finances, concerns about missing work, and language difficulties pose difficulties to accessing treatment (Abarca Tomás et al., 2013). I anticipate that our fourth article, “Migrant tuberculosis patient needs and health system response along the Thailand-Myanmar border”, on health system response to treatment barriers, makes the most significant contribution to the global TB and migration literature as response often occurs but is rarely documented in the literature (Richter et al., 2014). Health system response is like a shadow. If you look closely you can see it but it is rarely documented. Our study, while specific to the Thailand-Myanmar border, provides examples of how two organizations have responded and documents the resource intensive nature of this response which may be useful for other organizations who are developing

programming. It may also help to prompt further discussion on the need for responses that extend beyond the healthcare system.

Recently, there has been renewed interest in TB and migration specifically in Europe. The academic conversations surrounding TB control among migrant populations have offered screening prior to travel as a potential initiative to attempt to prevent migrants from travelling with TB from high burden countries to Europe (Aldridge et al., 2014; Coker et al., 2004; Dara et al., 2012; van der Werf & Lönnroth, 2014). While the national incidence of TB in European countries and Thailand is significantly different, both regions share the same characteristic of having long and porous borders. Our qualitative study brings to the discussion the importance of priority setting when developing policies for TB control among migrants. We began the study by looking at access to TB treatment for refugees and migrants and upon finding that the latter had good access to care we looked at the situation of documented and undocumented migrants in more depth. In the Thai context, we found that it is important to prioritize undocumented migrants for two reasons. Firstly, undocumented migrants have more difficulties accessing healthcare than migrants who are registered in the CMIH scheme. Secondly, undocumented migrants who have migrated using irregular means may experience living conditions during and following their migration that make them more susceptible to TB infection and disease. Based on our work, I would argue that strategies to address TB screening and treatment among undocumented migrants should also be prioritized in other regions as well. I believe there is value in recording the experience of undocumented migrants who often remain invisible within surveillance systems and to policy makers.

Theory

Our study makes a theoretical contribution by revising Levesque et al.'s (2013) conceptual framework for access to healthcare to make it relevant for migrant and refugee populations. By adding legal status and treatment cycling to the framework we bring these issues into the forefront. I anticipate that this revised framework will be useful for researchers and health care practitioners who are working with migrants and refugees in other contexts.

While I use the term ability throughout the thesis, there is some compatibility with Sen's (2009) capability approach. Similarly to Sen, in this thesis I considered real opportunity rather than hypothetical opportunity. Essentially we examined individuals' actualized opportunities to seek the healthcare they desire. We found that migrant's ability to access care is related to the social and financial resources that they have as well as their legal status. From a capability approach, we could argue that migrant's freedom to access healthcare is influenced by their legal status.

Practice and policy

Our findings are relevant to the stakeholders that participated in the project as well as treatment providers and public health officials on the other side of the Thai border in Myanmar. The results suggest that the catchment area for TB patients extends south to Bangkok and east to Yangon, Myanmar and that migrant and refugee TB cases treated at NGO clinics are not reported in the Thai public health surveillance system. These findings may serve as a point of departure for future discussions on measures to improve TB control in the Thailand-Myanmar border region. Our results imply that TB readily

crosses national boundaries and as a consequence organizations on both sides of the border need to work collaboratively to address the situation. Policy makers may wish to consider how they can respond to this challenge which extends beyond their jurisdiction as expressed by the slogan, “TB anywhere is TB everywhere” (World TB Day, 2007, np).

While our research is primarily qualitative, our results point towards the value of community and residential TB programs as a means to improve access to treatment and adherence. Treatment for TB reduces the spread of the bacteria and has benefits for individual patients as well as society. Successfully adhering to TB treatment also has benefits for the healthcare system as it reduces the likelihood that patients will develop MDR-TB which is more costly and resource intensive. To further investigate the dollar value of the benefits produced by these initiatives, researchers may want to develop a quantitative model. Specifically, analysts could estimate the cost of default (in terms of costs to the patient, costs to individuals who contract TB from the defaulter and the cost of MDR-TB treatment) and then estimate the value of adhering to TB treatment. This analysis would have to take into account the likelihood that defaulters will transmit TB to others and will ultimately contract MDR-TB. Cost savings would be estimated by establishing the reduction in default cases in comparison with standard treatment and multiplying the number of cases by the financial value attributed to TB adherence.

Limitations

As the data for this research project was collected in Tak province during a three month time period in the summer of 2014, the project results cannot be generalized beyond this time period. The political context along the Thailand-Myanmar border is

shifting and I believe it is important to keep the temporality of this work in mind. In 2016, when this thesis was being finalized, plans were being made to close the refugee camp which I anticipate will have implications for healthcare access along the border.

A second limitation of this work, is that we were only able to include patients who had successfully sought treatment. Despite this limitation, participants did express the barriers that they and other members of their community face and we anticipate that some of these may be similar for individuals who did not successfully navigate a pathway to care.

Due to resource limitations and logistical challenges, when developing the project we decided to conduct our research exclusively in Tak province and to not collect data in neighboring Kayin state, Myanmar.

Future research

While I believe that the results of this research project fulfill the study's objectives, they also lead to opportunities for future research. As described above, I anticipate that it could be valuable to create a quantitative model to assign a financial value to residential TB treatment. A second realm of future inquiry could be around the concept of the perfect patient and how this intersects with migration and drug-resistance.

Recommendations for policy and practice

Based on the study results I propose the following policy recommendations:

- Establish a bi-national policy and practitioner task force on TB that meets regularly to discuss TB control in the Thailand-Myanmar border region; and

- Review the Thai public health surveillance system and ensure that all TB cases within Thailand, regardless of origin, are enumerated in the records.

Conclusion

Our multi-methods inquiry into access to TB treatment for migrants and refugees has yielded contributions to the documented state of knowledge locally, as well as considerations for policy makers and health care providers along the Thailand-Myanmar border. More broadly, the project has made a theoretical contribution to the conceptualization of access to healthcare for migrant and refugee populations.

In conclusion, our research project suggests that in Tak province, Thailand access to TB treatment occurs at the intersection of health system accessibility, population ability and legal status.

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Appendix A: Map of Tak province created using Google Maps



Appendix B: Ethics Approval University of Ottawa

File Number: H02-14-08

Date (mm/dd/yyyy): 07/30/2014



Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

Ethics Approval Notice Health Sciences and Science REB

Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

<u>First Name</u>	<u>Last Name</u>	<u>Affiliation</u>	<u>Role</u>
Angel	Foster	Health Sciences / Others	Supervisor
Francois	Nosten	Medicine / Others	Co-Supervisor
Naomi	Tschirhart	Health Sciences / Population Health	Student Researcher

File Number: H02-14-08

Type of Project: PhD Thesis

Title: TB Surveillance Challenges and Treatment Barriers among Migrant and Refugee Populations in Tak province, Thailand

Approval Date (mm/dd/yyyy)	Expiry Date (mm/dd/yyyy)	Approval Type
07/30/2014	07/29/2015	Ia

(Ia: Approval, Ib: Approval for initial stage only)

Special Conditions / Comments:
N/A

Appendix C: Ethics Approval Tak Provincial Public Health Office



เอกสารรับรองโครงการวิจัย

ที่เป็นโครงการวิจัยที่ได้รับการรับรองจริยธรรมการวิจัยด้านสาธารณสุขในคน จังหวัดตาก

ตามที่ Mr.Naomi Tschirhart ซึ่งเป็นหัวหน้าโครงการ จะดำเนินการวิจัยเรื่อง “TB Surveillance Challenges and Treatment Barriers among Migrant and Refugee Population in Tak provinc,Thailand” ดาก โดยมีหัวหน้าโครงการวิจัยชื่อ Mr.Naomi Tschirhart เพื่อขอรับการพิจารณารับรองจริยธรรมการวิจัยในมนุษย์ จากคณะกรรมการจริยธรรมการวิจัยด้านสาธารณสุขในคน สำนักงานสาธารณสุขจังหวัดตาก หมายเลขเอกสารรับรองโครงการ No. TK๑...../...๒๕๕๗.....ซึ่งได้รับการรับรองจริยธรรมการวิจัยในคนแล้ว



The Ethical Approval Letter for the Public Health Research Project Involving People in Tak Province

According to Ms. Naomi Tschirhart (Research Project Leader) would like to conduct a research under the title of “TB Surveillance Challenges and Treatment Barrier among Migrant and Refugee Population in Tak Province, Thailand”. Ms. Naomi Tschirhart has requested an ethical review for her research project which involving people.

The Committee of Ethics in Research of the Tak Provincial Public Health Office has approved this research project with the file number TK 1/2557 to fully receive the ethical approval for the research project involving people.

Appendix D: Ethics Approval University of Oxford

Oxford Tropical Research Ethics Committee

University of Oxford
Joint Research Office
Churchill Hospital, Oxford OX3 7LE
Tel. +44 (0) 1865 (5)72346 fax +44 (0) 1865 (5)72228
E-mail:



Ms Naomi Tschirhart
C/O Institute of Population Health
University of Ottawa
1 Stewart Street, Room 300
Ottawa ON K1N 6N5

07 July 2014

Dear Ms Tschirhart

Full Title of Study: TB Surveillance Challenges and Treatment Barriers among Migrants and Refugee Population in Tak province, Thailand.

OXTREC Reference: 538-14

Thank you for your email of the 27 May 2014, and for your minimal risk application form. Other documents reviewed were:

Documentation	Version	Date
Protocol	V2.0	20/06/14
Scientific Review by Dr Podjane Jittamala		
Conditional Approval – University of Ottawa		19/03/14
Survey Participant Information Sheet	V2.0	20/06/14
Focus Group Participant Information Sheet and Informed Consent Form	V2.0	20/06/14
Key Informant Participant Information Sheet and Informed Consent Form	V2.0	20/06/14
Community Health Volunteer Questionnaire	V2.0	20/06/14
Focus Group Discussion Guide	V2.0	20/06/14
Key Informant Interview Guide	V2.0	20/06/14
Community Health Invitation	V2.0	20/06/14
Invitation for Patient Participation (Refugees)	V2.0	20/06/14
Invitation for Patient Participation (Appendix B Migrants)	V2.0	20/06/14
Invitation for Patient Participation (Appendix C Migrants)	V2.0	20/06/14
Invitation – Draft email (Key Informants)	V2.0	20/06/14

The OXTREC executive team reviewed the above application on the 01 July 2014 and gave approval for this study.

Approval is given for the first five years and subject to receiving the local ethical approval.

This approval will be fully implemented upon final consent of the full committee at the meeting on Thursday 17 July 2014.

APPENDIX E: Focus Group Discussion Guide

Focus Group Discussion Guide

Introductions

Hello, my name is (*interpreter*) and this is my colleague Naomi Tschirhart. Welcome to this focus group discussion. The purpose of this conversation today is to get a better understanding of the processes of accessing TB, TB-HIV or MDR-TB treatment, challenges that may exist and factors that help you to access healthcare for these conditions.

To begin, I'd like to review the consent form; I will read it aloud and feel free to ask me any questions or request any additional information. Once the questions are answered we will ask each participant to provide their oral consent to participate. Participation in this project is voluntary and your decision to participate will not affect your access to TB treatment. *[Read consent form out loud. Interpreter to collect oral consent from participants.]*

Your thoughts, opinions and experience are important to us and are extremely valuable. Feel free to contribute in the language of your choice. Our interpreter speaks Karen, Burmese and English. We would like to record this conversation so that we collect the details of this conversation. To help capture what you are saying please take turns speaking. We are now turning on the tape recorder.

Please go around the room and introduce yourself. It would be great if you could share where you are from and the length of time that you have been in Thailand.

Discussion Guide

Opening Questions

1. For individuals who do not have TB, TB-HIV or MDR-TB

I'd like to begin by asking you about your background knowledge of TB. Please tell me what you know about TB and where you collected this information from.

- a. Probe: How does someone get TB?
- b. Probe: What are symptoms of TB?

For patients who have accessed treatment in Thailand

I'd like to begin by asking you about your background knowledge of TB. Please tell me what you know about TB and where you collected this information from.

- a. Probe: How does someone get TB?
- b. Probe: What are symptoms of TB?
- c. Probe: How did you find out that you have TB?
- d. Probe: Did you know that you had TB before you sought medical treatment?

[Interpreter will provide additional evidence based information regarding the transmission and symptoms of TB if necessary.]

2. For individuals who do not have TB, TB-HIV or MDR-TB

In your community are people treated differently if they have TB?

- a. Probe: How about TB-HIV or MDR-TB?

For patients who have accessed treatment in Thailand

In your community are people treated differently if they have TB?

- a. Probe: How about TB-HIV or MDR-TB?
- b. Probe (response): Drawing from your personal experience, how did your family members respond to your diagnosis?
- c. Probe (response): How about members of the community where you live?
- d. Probe (participation): Are there certain activities that you cannot participate in because you have TB?

Processes to Access Treatment

1. For individuals who do not have TB, TB-HIV or MDR-TB

If you or someone in your family had tuberculosis or symptoms of a respiratory infection, under what conditions would you decide that it is necessary to access treatment?

- a. Probe: Who would be involved in this decision making process?

For patients who have accessed treatment in Thailand

Can you describe the moment when you decided that you needed to access treatment for TB?

- a. Probe: What made you decide to seek treatment?

For individuals who do not have TB, TB-HIV or MDR-TB

2. If you or someone in your family has tuberculosis or a respiratory infection, where would you go to access treatment?

For patients who have accessed treatment in Thailand

Can you describe how you came to the clinic where you are receiving treatment?

- a. Probes: Were you referred? Who did you contact first?

Barriers

Now I'd like to move on to look at treatment availability and some of the challenges that may exist for people accessing treatment for TB, MDR-TB and TB-HIV co-infection.

1. For individuals who do not have TB, TB-HIV or MDR-TB

Can you describe the types of medical services for TB, TB-HIV and MDR-TB that are available close to your home?

- a. Probe (Accessibility): How far would you have to travel to access these services?

- b. Probe (Affordability): If you or someone in your family had symptoms of a respiratory infection or tuberculosis would treatment cost be a barrier to accessing healthcare?
- c. Probe (Affordability/Accessibility): Are travel costs a factor in seeking treatment?

For patients who have accessed treatment in Thailand

Can you describe the types of medical services for TB, TB-HIV and MDR-TB that are available close to your home?

- a. Probe (Availability): How far did you have to travel to access these services?
- b. (Affordability): In accessing treatment for TB, was treatment cost a factor in deciding when you would seek treatment?
- c. Probe (Affordability/Availability): Were travel costs a barrier to accessing treatment?

2. For individuals who do not have TB, TB-HIV or MDR-TB

Please describe any challenges or difficulties that you or a family member might experience in accessing treatment for TB, MDR-TB or TB-HIV treatment in Thailand.

- a. Probe (Gender): Are there specific work or household responsibilities specific to men or women that could impact getting treatment?
- e. Probe (Legal Status): Would legal status be a barrier to treatment?
- f. Probe (Language): In which language(s) would you feel comfortable receiving treatment?
- g. Probe (Language): Would language be a barrier to accessing treatment?
- h. Probe (SES/Pressure to work): Is it difficult to take time off work to attend medical appointments?
- i. Probe (SES/Pressure to work): If you or someone in your family had symptoms of a respiratory infection or tuberculosis would pressure to work be a barrier to accessing healthcare?

For patients who have accessed treatment in Thailand

Please describe any challenges or difficulties that you experienced in accessing treatment for TB, MDR-TB or TB-HIV treatment in Thailand.

- a. Probe (Gender): From your personal experience, can you describe any responsibilities related to being a man/woman that impacted your ability to access treatment?
- b. Probe (Legal Status): Was legal status a barrier to accessing treatment?
- j. Probe (Legal Status): In accessing treatment, was legal status a factor in choosing where you would access treatment?
- k. Probe (Language): In which language(s) would you feel comfortable receiving healthcare?
- l. Probe (Language): In accessing treatment for TB, was language a factor in choosing where you would access treatment?
- m. Probe (Language): Was language a barrier to accessing treatment?

- n. Probe (SES/Pressure to Work): Is it difficult to take time off work to attend medical appointments?
- o. Probe (SES/Pressure to Work): In accessing treatment for TB, was pressure to work a factor in deciding when you would seek treatment?

3. *For individuals who do not have TB, TB-HIV or MDR-TB*

Treatment for Tuberculosis typically lasts six months and is much longer for TB-HIV co-infection or multi drug resistant TB (MDR-TB).

- a. Probe (Duration): If you or someone in your family had symptoms of a respiratory infection or tuberculosis would the duration of treatment be a barrier to accessing treatment?

For patients who have accessed treatment in Thailand

Treatment for Tuberculosis typically lasts six months and is much longer for TB-HIV co-infection or multi drug resistant TB (MDR-TB).

- a. Probe: (Duration): When deciding to take treatment for TB, was the duration of treatment explained to you?
- b. Probe (Duration): Was duration of treatment a factor in your decision to undertake treatment? Is duration of treatment a factor in your decision to continue and/or complete treatment?

Treatment adherence/completion

1. *For individuals who do not have TB, TB-HIV or MDR-TB*

If you or someone in your family has symptoms of a respiratory infection or tuberculosis, what enabling resources would help this individual to complete their treatment?

- a. Probes: Family or community support
- b. Financial resources
- c. Availability of services
- d. Free or low cost services
- e. DOT by community health volunteers or community health workers

For patients who have accessed treatment in Thailand

Can you describe some of the things in your life that assisted you in adhering to your TB treatment plan?

- a. Probes: Family or community support
- b. Financial resources
- c. Availability of services
- d. Free or low cost services
- e. DOT by community health volunteers or community health workers

Enabling Resources

While we have discussed some of the factors that make it difficult to access treatment, I am sure there are also factors that help people in your community to get the treatment

they need. The next set of questions are about “enabling resources” or simply resources that help someone to gain access to healthcare.

1. For individuals who do not have TB, TB-HIV or MDR-TB

If you or someone in your family has symptoms of a respiratory infection or tuberculosis, what types of resources would help this individual to access treatment?

- a. Probe: Family or community support
- b. Probe: Financial resources
- c. Probe: Availability of services
- d. Probe: Free or low cost services
- e. Probe: Referral by community health volunteers or community health workers

For patients who have accessed treatment in Thailand

Can you describe some of the resources in your life that assisted you in accessing treatment for TB?

- a. Probe: Family or community support
- b. Probe: Financial resources
- c. Probe: Availability of services
- d. Probe: Free or low cost services
- e. Probe: Referral by community health volunteers or community health workers

Final Questions

Thank you so much – our discussion is almost complete. In closing...

1. For individuals who do not have TB, TB-HIV or MDR-TB

Do you have any comments about the process of accessing treatment for TB, TB-HIV or MDR-TB?

- a. Probe: Is there anything else you would like to share?

For patients who have accessed treatment in Thailand

From your experience, do you have any additional comments about the process of accessing treatment for TB, TB-HIV or MDR-TB?

- a. Is there anything else you would like to share?

Wrap up

Thank you so much for participating today. We would be pleased to answer any questions you might have. If you would like to receive a summary of the research results please provide us with your email or mail address on the card provided before you leave. In addition, be sure to see me on your way out to receive a reimbursement for your travel expenses.

APPENDIX F: Key Informant Interview Guide

Key Informant Interview Guide

Introduction

Please tell me about your background. How did you get involved in this field?

Please describe your role in the organization where you work.

Which target populations does your organization work with?

Part I Surveillance

Do you participate in or oversee the collection of infectious disease data?

- (If yes) Please explain your role and the duration that you have been in this role.
- (If no, proceed to the next question).

Can you describe how TB cases are captured by the surveillance system?

- Who collects the information?
- How often is it collected?
- Where is it sent?

Do you participate in or oversee the analysis of infectious disease data?

- (If yes) Please explain your role and the duration that you have been in this role.
- (If the participant has answered no to both collection and analysis, proceed to part IV Treatment).

Is the collection of TB data done through administrative records (passive) or is it actively collected by the public health department?

How about HIV cases?

Looking specifically at HIV TB co-infection, does the surveillance system collect data on the number of new cases of TB-HIV?

- Is there a mechanism to ensure that these cases aren't counted twice (for example counted as both TB and TB-HIV)?

Does the surveillance system collect data on the number of new cases of MDR-TB?

- Is there a mechanism to ensure these cases aren't counted twice (for example counted as both TB and MDR-TB)?

Part II Surveillance Barriers

Can you identify any barriers to surveillance in general?

- How about barriers specific to TB?

- How about barriers specific to MDR-TB?
- How about barriers specific to HIV?
- How about barriers specific to TB-HIV?

Part III Surveillance Adaptation/Responsiveness

Over the past two years has the way surveillance data is collected changed?

- (If yes) How?
- (If yes) What are some of the reasons for these changes?

Has the introduction of the migrant information center at the Mae Sot hospital in 2011 changed the way surveillance data is collected or analyzed in Tak province?

How has the organization where you work responded to the barriers to collecting surveillance data on TB, TB-HIV and MDR-TB?

In your opinion, what types of improvements or adaptations could help to improve the surveillance system?

Part IV Treatment

Do you have experience providing TB, TB-HIV or MDR-TB treatment and/or overseeing the provision of such treatment? (If yes continue, If no end interview).

Please describe your role in treatment provision and the duration of time that you have been in this role.

Does your organization provide treatment?

- For TB?
- For MDR-TB?
- For HIV?
- For TB-HIV?

If your organization does not provide treatment for some of these conditions, where are patients referred to?

From your experience what types of barriers do individuals with TB face in accessing treatment?

- Probes: self perceived need, gender responsibilities, legal status, language, pressure to work, treatment cost, low health knowledge, treatment duration.

Are the types of barriers to access different for MDR-TB as compared to TB?

- Please describe.

Running head: ACCESS TO TUBERCULOSIS TREATMENT FOR MIGRANT

In your opinion, are there different types of barriers for accessing HIV treatment as compared to TB?

- Please describe.

In considering the barriers to accessing treatment what types of barriers do individuals with a TB-HIV co-infection face in accessing treatment?

- Are these different than individuals that are not co-infected and have only a single diagnosis of either TB or only HIV?

In your experience, is the length of treatment a concern for patients accessing TB treatment?

- How about MDR-TB treatment?

Looking at barriers to continuing and completing treatment for TB, MDR-TB and TB-HIV, what can you identify as the main challenges?

Does your organization have mechanisms to track whether patients diagnosed with TB start and/or complete treatment? If yes, please describe.

Part V Responsiveness

In the last two years, has the organization you work with changed the way treatment for TB is delivered?

- (If yes) How?
- (If yes) What are the reasons for these changes?

Have there been any treatment delivery changes for MDR-TB?

- How about TB-HIV?

If there have been treatment delivery changes, what prompted these changes?

How has the organization where you work responded to the barriers to accessing treatment experienced by individuals with TB?

- How has the organization responded to barriers to accessing treatment for individuals with MDR-TB?
- How has the organization responded to barriers to accessing treatment for individuals with TB-HIV?

In your opinion, what types of further improvements or adaptations could help to improve access to TB, TB-HIV and MDR-TB treatment among your target population(s)?

- Probe: If you could take one action, what would it be?

APPENDIX G: Community Health Volunteer Questionnaire

Variable	Questions	Response Options				
Contribution to TB, HIV, TB-HIV and MDR-TB Treatment						
1	In the last 12 months have you provided treatment for TB ? (If yes proceed to question 2, If no proceed to question 4)	1- Yes	2- No			
2	In the last 12 months have you assisted in supervising directly observed treatment (DOT) ie. where you observe the patient taking their medicine daily?	1- Yes	2- No			
3	To which population did you provide TB treatment? (check all that apply) <input type="checkbox"/> maternal <input type="checkbox"/> neonatal (newborn < 28 days old) <input type="checkbox"/> children <input type="checkbox"/> women <input type="checkbox"/> men					
4	MDR-TB is TB that is resistant to isoniazid and rifampicin. In the last 12 months have you provided treatment for MDR-TB ? (If yes proceed to question 5, If no proceed to question 7)	1- Yes	2- No			
5	Have you assisted in supervising directly observed treatment (DOT) for MDR-TB ie. where you observe the patient taking their medicine daily?	1- Yes	2- No			
6	To which population did you provide MDR-TB treatment? (check all that apply) <input type="checkbox"/> maternal <input type="checkbox"/> neonatal (newborn < 28 days old) <input type="checkbox"/> children <input type="checkbox"/> women <input type="checkbox"/> men					
7	In the last 12 months have you provided treatment for HIV/AIDS ? (If yes proceed to question 8, If no proceed to question 9)	1- Yes	2- No			
8	To which population did you provide HIV/AIDS treatment? (check all that apply)					

Variable	Questions	Response Options				
	<input type="checkbox"/> maternal <input type="checkbox"/> neonatal (newborn < 28 days old) <input type="checkbox"/> children <input type="checkbox"/> women <input type="checkbox"/> men					
9	In the last 12 months have you provided treatment for TB-HIV co-infection? (If yes proceed to question 10, If no proceed to question 12)	1- Yes	2- No			
10	In the last 12 months have you assisted in supervising directly observed treatment (DOT) for TB-HIV ie. where you observe the patient taking their medicine daily?	1- Yes	2- No			
11	To which population did you provide TB-HIV treatment? (check all that apply) <input type="checkbox"/> maternal <input type="checkbox"/> neonatal <input type="checkbox"/> children <input type="checkbox"/> women <input type="checkbox"/> men					
Referral for testing/treatment						
12	In the last 12 months have you referred the confirmed TB patients in your catchment area for HIV testing? (If “never” go to question 14)	1- Never	2- Rarely	3- Some of the time	4- Most of the time	5- Always
13	Who did you refer them to? <input type="checkbox"/> Community Health Worker <input type="checkbox"/> Local Clinic <input type="checkbox"/> Other (describe) ----- --					
14	In the last 12 months have you referred the HIV patients in your catchment area for TB testing? (If “never” go to question 16)	1- Never	2- Rarely	3- Some of the time	4- Most of the time	5- Always
15	Who did you refer them to? <input type="checkbox"/> Community Health Worker <input type="checkbox"/> Local Clinic <input type="checkbox"/> Other (describe) ----- --					
16	In the last 12 months have you referred suspected TB cases in your catchment area for TB testing?	1- Never	2- Rarely	3- Some of the	4- Most of the	5- Always

Variable	Questions	Response Options				
				time	time	
17	In the last 12 months have you referred suspected HIV/AIDS cases in your catchment area for HIV testing?	1- Never	2- Rarely	3- Some of the time	4- Most of the time	5- Always
Contribution to surveillance						
18	If you find a new suspected case of TB in your catchment area, do you notify someone? (If yes go to question 19, if no go to question 20)	1- Yes	2- No			
19	Who do you notify? () Community health worker () Thai public health clinic () Other -----					
20	If you find a new suspected case of HIV/AIDS in your catchment area, do you notify someone? (If yes go to question 21, if no go to question 22)	1- Yes	2- No			
21	Who do you notify? () Community health worker () Thai public health clinic () Other -----					
22	In the last 12 months have you collected data on infectious disease in your catchment area? (If yes go to question 23, if no go to question 27)	1- Yes	2- No			
23	How did you collect this information? () door to door data collection () record keeping () Other -----					
24	Who was this information sent to? () Community health worker () Thai public health office () Other -----					
25	In the last 12 months have you collected data on the following (check all that apply) () TB () HIV/AIDS () TB-HIV () MDR-TB					
Demographic Information						
26	What is your sex?					

Variable	Questions	Response Options				
	<input type="checkbox"/> Male <input type="checkbox"/> Female					
27	How old are you? <input type="checkbox"/> < 20 <input type="checkbox"/> 20-29 <input type="checkbox"/> 30-39 <input type="checkbox"/> 40-49 <input type="checkbox"/> 50-59 <input type="checkbox"/> > 59					
28	How long have you been a community health volunteer? <input type="checkbox"/> < 6 months <input type="checkbox"/> 6 <12 months <input type="checkbox"/> 1 < 2 years <input type="checkbox"/> 2 < 3 years <input type="checkbox"/> 3 or more years					
29	What is your legal status in Thailand? <input type="checkbox"/> Undocumented migrant <input type="checkbox"/> Documented migrant <input type="checkbox"/> Thai citizen <input type="checkbox"/> Refugee <input type="checkbox"/> Prefer not to answer					
30	What languages do you speak? <input type="checkbox"/> Karen <input type="checkbox"/> Burmese <input type="checkbox"/> Thai <input type="checkbox"/> Other -----					
31	What languages do you read? <input type="checkbox"/> Karen <input type="checkbox"/> Burmese <input type="checkbox"/> Thai <input type="checkbox"/> Other -----					