

# Engaging women volunteers of high socioeconomic status in supporting socioeconomically disadvantaged tuberculosis patients in Chiang Rai, Thailand

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**Problem:** The 2008 tuberculosis (TB) surveillance of Chiang Rai Hospital, Chiang Rai, Thailand reported that 8.4% of Thai, 22.7% of hill tribe minority and 25% of migrant patients ( $n = 736$ ) defaulted from treatment.

**Context:** TB patient management in Chiang Rai is complicated due to poverty and HIV stigma. A previous study shows unaffordable travel expense was one of the reasons of patient default.

**Action:** We engaged Chiang Rai women's organizations whose members are of high socioeconomic status to support poor TB patients financially and socially. A group of women formed a team to support these TB patients ( $n = 192$ ) by raising and sustaining funds and providing home visits ( $n = 37$ ). TB surveillance and patient-fund register data were used to evaluate TB treatment outcomes.

**Outcome:** The success of TB treatment was significantly higher for patients receiving financial support (relative risk [RR]: 1.351; 95% confidence interval [CI] 1.20–1.53;  $P < 0.000$ ). Lower death rates in all groups were observed among patients receiving financial support. However, financial assistance alone did not improve treatment outcomes for migrant patients. Thirty-seven patients (25 Thai, eight hill tribe, four migrants) who were visited by women volunteers at home achieved 95% TB treatment success.

**Discussion:** It is possible to involve volunteers to support poor TB patients. Willingness to support TB patients was driven by presenting provincial TB epidemiology information, research data on the experience of poor patients and the inspiring experiences of other women volunteers. Future research should investigate the reasons for the high treatment success among patients who received home visits.

## PROBLEM

Regardless of a country's economy or tuberculosis (TB) prevalence, TB is a disease associated with poverty,<sup>1</sup> and Thailand is no exception. Although the World Bank has ranked Thailand as an upper-middle-income country, the income gap between the rich and the poor is one of the most unequal in Asia.<sup>2</sup> The World Health Organization (WHO) classified Thailand as a country with high prevalences of TB, HIV and TB with HIV co-infection (TB/HIV).<sup>3</sup> Since 1998, WHO has listed Thailand as one of the 22 high TB-burden countries. Chiang Rai, Thailand's northernmost province, has a high density

of hill tribe minorities and migrants from Myanmar. Of the 1.2 million people in Chiang Rai, about 18 460 people are living with HIV; the TB notification rate in 2011 was 153 per 100 000 (23% TB with HIV co-infection). The Chiang Rai provincial TB surveillance data indicates that, on average, one patient dies of TB every 36 hours in the province.

Chiang Rai Hospital (CRH), the largest provincial government hospital, provides free TB diagnosis and treatment for patients who declare that health-care costs are unaffordable. Patients are requested to visit the hospital biweekly or monthly, depending on their

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clinical conditions. Although treatment is free, TB patient management in CRH is complicated due to poverty, HIV stigma, language and cultural differences, as well as the legal status of some patients. The 2007 TB surveillance of CRH ( $n = 736$ ) reported that 8.4% of Thai, 22.7% of hill tribe minority, and 25% of migrant patients, defaulted from treatment. Our previous study<sup>4</sup> reported that a majority of TB patients had to borrow money during their TB treatment course (six to nine months). Unaffordable travel expense was referred to as a main cause of treatment interruption, especially for hill tribe and migrant patients. Due to language barriers, these cases had to be accompanied to the hospital, which doubled the travel expense. During the investigation into reasons for default from TB treatment, we learnt about the difficulties experienced by poor patients. Older children who lost their parents had to quit school and go to work; younger children were raised by elderly grandparents.<sup>5</sup>

## CONTEXT

In 2008 we established the "Center for Sharing," a TB patient-fund at CRH providing travel and food support for those who needed it. The initial 100 000 Thai baht (approximately US\$ 3300) was granted from the Stop TB partnership.<sup>6</sup> Our greatest challenge was devising a way to sustain the patient-fund after the initial grant was exhausted.

## ACTION

To ensure continuity of the patient-fund, we explored the feasibility of fund-raising in a sustainable manner by involving Chiang Rai women's organizations whose members are of high socioeconomic status. We obtained a list of women's organizations in Chiang Rai through an internet search, contacted the provincial social development and human security office and discussed our plans with the chair of a menopause clinic club. Subsequently, we organized the first workshop by inviting 33 women from nine women's organizations in Chiang Rai. The five-hour workshop included the following sessions:

- Pre- and post-workshop tests about TB;
- Information about TB disease;
- Chiang Rai TB epidemiology;
- Experiences of poor TB patients;

- TB control case studies on the role of women volunteers in India, Bangladesh, Indonesia and Japan; and
- Group discussion on "Can women's organizations in Chiang Rai contribute to TB care?"

The first workshop revealed most women were highly aware of the serious HIV situation in Chiang Rai, but they thought of TB as a disease of the past. Although the experiences of women volunteers from low-income countries were presented, the participants reported relating best to the Japanese volunteers' experiences. The slogan "Eradicate TB with women's hands and hearts" inspired the group, and they believed they could develop a similar project in Chiang Rai.

Two follow-up workshops to discuss and plan actions were organized. By the end of the third workshop a group was formed called "Women Volunteers to Eradicate TB." The group selected a chair, vice-chair, treasurer and secretariat and invited the TB and HIV doctors from CRH to be advisers. The volunteers performed two major activities to support TB patients: fund-raising for the TB patient-fund and home visits.

### Fund-raising for TB patient-fund

The volunteers raised funds to support TB patients by organizing a charity gala dinner, selling products at provincial festivals and conferences and collecting donations from individual volunteers and women's organizations. The TB patient-fund staff identified patients who needed financial assistance for transportation and living expenses by interviewing TB patients with a simple poverty screening questionnaire.<sup>7</sup> The questionnaire included the following: (1) Do you have health insurance? (2) Do you have less than US\$ 3 for the whole family or did you experience a food shortage during the last month? (3) Are you able to pay for travel to the TB clinic? (4) Do you have family members, friends or relatives to help when encountering a financial crisis? The support ranged from 100 to 4000 Thai baht per visit depending on the patient's circumstances.

### Home visit

In addition to receiving financial support from the TB patient-fund, some patients received home visits from the volunteers. The criteria for a home visit included: extremely poor TB patients, living alone, living with

Table 1. Treatment outcome of tuberculosis patients receiving financial support from the patient-fund, classified by ethnicity (June 2009 to March 2011)

Patients' ethnicity	Receiving financial support		Tuberculosis treatment outcome (%)*				RR (95% CI)	p-value
	(Yes/No)	n	Success rate	Death	Treatment failure	Default		
Thai	Yes	104	72.1	23.1	0	4.8	1.42 (1.24–1.67)	$P < 0.0$
	No	443	50.1	37.4	2.3	10.2	Reference	
Hill tribe minorities	Yes	75	72.0	10.7	2.7	14.7	1.12 (0.94–1.47)	$P = 0.1$
	No	85	61.2	16.5	4.7	17.7	Reference	
Migrants	Yes	13	30.8	7.7	0	61.5	0.75 (0.31–1.84)	$P = 0.5$
	No	39	41.0	36.0	0	23.1	Reference	
Totals	Yes	192	69.3	17.2	1.0	12.5	1.35 (1.20–1.53)	$P < 0.0$
	No	567	51.6	34.2	2.5	12.2	Reference	

RR – relative risk; CI – confidence interval

\* Success rate – cured and completed treatment; Default – lost to follow-up &gt; 2 months

Note: Data from Chiang Rai Hospital's TB register and TB patient-fund register.

elderly caregivers or being isolated from the community and patient consent to home visit. In each visit, four to six volunteers visited the patient at home. The volunteers usually brought milk, eggs, clothes and cash to support the patient. The volunteers gave encouragement to patients to overcome their disease and difficulties. Each home visit lasted about 30 minutes.

## Evaluation

After implementing these activities for more than 15 months, we analysed the TB register and patient-fund records and evaluated TB treatment outcomes of patients receiving and not receiving financial support. A group discussion with the members (10 women) who most frequently joined the activities was organized to explore the volunteers' motivations and challenges.

## OUTCOME

### TB treatment outcome of patients receiving only financial support

Of the total 759 TB patients, 72.1%, 21% and 6.9% were Thai, hill tribe, and migrant patients, respectively (Table 1). Nineteen per cent of Thai, 47% of hill tribe and 25% of migrant TB patients received financial support from the TB patient-fund. The overall treatment success rate of patients who received financial support was significantly higher than patients who did not receive financial support (relative risk [RR]:1.35;

95% confidence interval [CI]: 1.20–1.53;  $P < 0.000$ ). Lower death rates in all groups were also observed among patients receiving financial support. However, financial assistance alone neither increased treatment success nor reduced default for migrant patients. The proportion of hill tribe patients who received support had higher treatment success and lower default rates compared to patients who did not receive support, but this was not significantly different. In addition to supporting the patients, the patient-fund also supported the travel for 26 children with close contact to TB patients, access to TB screening and TB preventive therapy.

### TB treatment outcome of patients receiving financial support and home visit

Between June 2009 and March 2011, 37 patients (five children, 17 women and 15 men) were visited by the volunteers at home. They were 25 Thai, eight hill tribe and four migrant patients. Sixteen patients (43%) had TB with HIV co-infection. Remarkably, although these patients were considered to be either very poor or having complicated psychosocial issues, the treatment success rate of these 37 patients was 95%; two cases died (both were Thai, HIV-positive) and none defaulted. This project was not able to determine the reasons for the high treatment success of these patients. Some patients, especially the patients living alone or patients who were isolated from family and community reported feeling honoured and grateful to have the volunteers visit. One senior male patient living alone said, "It's just like a

dream, I have never thought this will happen to my life. Several people came to visit me...Thank you...Thank you so much."

### Characteristics of the women volunteers, their motivations and challenges

Since June 2009, the women's organizations that have consistently supported TB patients in Chiang Rai have been the Red Cross Chapter, the Model-Mother group, the Women's Cultural Promotion Association, the Women Volunteer for Civil Defence Association and the Senior Smart-brain volunteers. The Business and Professional Women's Association has participated with annual donations to the patient-fund. About 36 women regularly participated in the volunteer activities. More than half of the volunteers were aged over 60 years (range: 37–79 years old) and had university educations. They were retired senior government officers, health staff members, business owners or wives of high-level officials such as the governor and the hospital director. Most volunteers originated and lived in Chiang Rai. The majority of these women were members of two to five women's or volunteer organizations. Many of them knew each other and had volunteered together for many years. Some women had experience visiting disaster victims or disabled people. However, visits to TB patients' homes were new to all of them.

The volunteers found home visits challenging due to bad road conditions, especially in the rainy season. Several senior women said their family asked them not to visit patients' houses for fear of TB transmission. However, the volunteers felt home visits substantially encouraged patients and family members. Volunteers felt that their home visits may have also helped reduce TB and HIV stigma because community people observed the women visit the patients at home and interact as friends.

Group discussion with the volunteers showed that the major reasons for volunteering and supporting poor TB patients were Buddhism and the traditional Thai value that doing charity is a virtue. They plan to serve as volunteers as long as their physical health allows.

## DISCUSSION

To our knowledge, this is the first report from a TB high-burden country in which women with high socioeconomic status have been involved in TB care for fund-raising and home visits. Although studies from Bangladesh, Indonesia,<sup>8</sup> India<sup>9</sup> and Iraq<sup>10</sup> reported the important role of women volunteers as treatment supporters for TB, those volunteers were women living in the same community or having comparable socioeconomic status with TB patients. Several studies reported the role of financial support and social interventions in improving the TB situation for poor patients.<sup>11–14</sup> However, published literature describing the process of implementation is lacking.

This paper fills in the current knowledge gap by describing the process of engaging women volunteers with high socioeconomic status to financially and socially support poor TB patients. Willingness by these women to support the patients was driven by presenting the TB situation, providing research data on the experiences of poor patients and the experiences of women volunteers from other countries. The motivation to follow the Japanese women volunteers may be influenced by "Japanization." It has been suggested that since 1987, Thai people seem to respect and appreciate Japan as Asia's leading country for social, economic and technological advancement.<sup>15</sup> Mobilizing and engaging women organizations to support poor TB patients may be applicable in other settings where medical and health staff of TB services wish to support poor patients. The patients visited by women volunteers achieved very high treatment success rates despite being very poor and experiencing psychosocial difficulties. Future research should apply qualitative research to investigate the reasons for the high treatment success among patients who received home visits. A rigorous qualitative study should elicit how patients and women volunteers perceived the support.

In this paper, we report treatment outcomes from programme implementation, not from a research procedure. The stage of HIV infection, access to antiretroviral drugs and other clinical conditions may affect treatment outcome but were not available for the

analysis. Based on the limited data and methodology, we cannot conclude the effectiveness of the financial support and home visits. However, the overall treatment success of the patients receiving support was significantly higher than that of patients not-receiving support. The analysis by ethnicity showed high default rates in hill tribe and migrant patients; financial assistance alone may not be sufficient to assist these groups complete the long-term TB treatment.

### Conflicts of interest

None declared.

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# 「ストップ結核…私が生きている間に」 タイ・チェンライ県の女性達による結核対策への貢献

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WHO（世界保健機関）とストップ結核パートナーシップは、2012年の世界結核デーのテーマとして“Stop TB in my lifetime”を掲げました。これは、世界の人々に、一人一人が自分の生涯でこの世から結核がなくなることを目にしたいとの意思を表明することにより、この古い病気の制圧に参加してもらうという運動です。ここでは、チェンライ県における社会的・経済的地位の高い富裕層の女性グループが、今年の世界結核デーのテーマに応じた結核対策においてどのような役割を担っているのかをご紹介します

## タイにおける結核

タイはWHOが定める世界の結核高まん延国22カ国のうちの1つに指定されています。2010年の結核患者数は64,512名と発表されており、1時間に1人の結核による死亡者が出ています。結核の罹患率が高いチェンライ県は、新規結核患者が年間2,000名近くにのぼります。またこの県では、平均33時間毎に1人の結核死亡者が出ています。現在、タイ政府は健康保険制度の下、タイ国民身分証明書を持つすべての人たちに無料で結核検査、治療サービスを提供しています。これにより貧困層の負担が大幅に軽減されるものの、結核を治療することは容易なことではありません。これについて、チェンライ県での研究により様々な原因が判明しています。たとえば薬が無料であっても、患者は貧困のため十分な治療が受けられていません。結核患者の半数以上が治療期間、親戚兄弟から借金をせざるを得ない状況にあります。また、結核患者は周囲から差別を受け落胆し、治療する気を失ってしまうという問題もあります。高齢の患者については、孤独感を紛らわせるため飲酒に走るケースも多くみられます。チェンライ県では貧困層のタイ人結核患者の他に、様々な部族（山岳民族）や不法滞在の外国人の結核患者の問題もあります。これは、病気の治療をする上での障害となっており、患者は警察から逃げるだけでなく、病気からも逃げがちで、重症になってからはじめて病院に行くことになってしまいます。



チャリティー・ディナー…収益は貧困結核患者に贈呈されました。この一晚の10万バツが何百人もの患者を助けます。

次のケースは、貧困層の場合、治療薬が無料であっても、通院費用や食料がなければ病気を治すことはできず、同時に子供たちにも大きな影響を与えていることを示しています。

## 生きるために戦う…

デートくん（13歳）は、父親、母親、5歳の妹の家族4人を養うために学校を辞めなければなりません。デートくんはタイボクシング（ムエタイ）と建設の仕事で生活を支えています。彼の両親は結核患者で、HIVにも感染しています。そのため父親は仕事ができず、収入がありません。次の薬をもらいに病院に行くための交通費については言うまでもありません。1日1食の食事さえも大変なことです。これが、この両親が結核治療を十分に受けられない理由です。

もしこの両親が結核とエイズで命を失えば、デート君とその妹の生活はどのようなものになるのでしょうか。

## 小さな子供が病気の母を支える

ミーさん（30歳）は、ラフ族でムアン郡（県庁所在地）と呼ばれる地区に住んでいます。村は自然が多く残された状態のため、雨季の時期は病院への往来がとても大変です。ミーさんは結核に2度罹患しました。今回は合併症のため、初めて結核にかかった時よりも重症です。ミーさんの母親もまた結核患者で、一つ離れた村に住んでいます。夫は随分前に麻薬中毒になり、いなくなっていました。そのため、ミーさんの面倒を見ることができるのは5歳の娘です。この小さな娘が付きっきりで病気の母親の面倒を見、さらに森の中に入って竹の子を探し、自分の母親と3歳の妹に食べさせているのです。ですが、結局は結核と合併症がミーさんの命を奪ってしまいました。

チェンライ県に上述のような結核患者とは対照的な富裕層の女性グループがあります。この女性グループは、タイとチェンライ県の結核の状況について学んだことを機に、また日本の結核予防婦人会の結核対策への貢献に感銘を受け、自らを「結核を無くす女性ボランティア」と名づけ立ち上がりました。メンバーの年齢層は45～79歳で平均年齢は60歳過ぎです。メンバーは定年退職した公務員、県高官の妻、県赤十字代表の妻、県知事の妻、県立病院長の妻や民間企業の女性社長など、経済的余裕のある方々です。これらの女性の多くは、赤十字ボランティア、賢母クラブ、土地保護女性ボランティア、女性文化振興協会、女性実業

家等チェンライ県で活躍するグループのメンバーでもあります。

女性ボランティアは結核患者を支援する3つの活動を実施しています。貧困層の結核患者への資金援助、結核患者への家庭訪問、結核の治療薬袋詰め等の活動です。このボランティア活動に参加することにより、勲章や賞状は与えられませんが、結核患者からの感謝の気持ちや溢れる笑顔に代えられるものではありません。

結核患者がボランティアに会って流すうれし涙

女性ボランティアグループは、アルコール依存等により家族に見捨てられた結核患者や、また周囲からの差別に苦しむ結核患者の家を自ら率先して訪問しています。山岳民族の家への道は非常に困難で、車で行こうにも家まで辿り着く道路がありません。女性ボランティアの中には80歳近くの女性もいますが、それでも患者の家を訪問するため日差しをものともせず、高い山を登って行きます。患者の家といっても、木の切れ端をつなぎ合わせただけの、ほとんど家とは呼べない作りのものもあり、雨漏りする屋根も多い状況でした。患者の家では地面に座り、薬を最後まで飲むようにと励ましました。

“皆さん会いに来てくれてありがとう。…家まで来てくれるなんて夢にも思いませんでした。本当に嬉しい…”。



華やかなドレスを脱ぎ捨て貧困患者を訪問しに山を登ります。



道がぬかるんでいるため靴の泥を洗い落としています。



穴だらけの屋根から雨が漏れ、女性ボランティアの背中を濡らしています。

隣人の物置小屋に住む結核患者であるブンさんが喜びのあまり涙を流しています。ブンさんは、何十年も1人で暮らしてきました。彼の妻は、ブンさんの酒癖の悪さに耐えきれず出て行ったのです。彼は、気にかけてくれる人は誰もいない孤独な生活に疲れ果てていました。ですが、ある日今までに会ったこともないような富裕層の女性たちが訪問し、励ましに来てくれました。女性ボランティアが訪問した38名の貧困患者のうち2名がエイズとの合併症により死亡、他36名は全員結核の治療薬を必要分すべて服用していることが分かりました。

チェンライ県結核ボランティアの活動により、チェンライ県における何百人ものタイ人の貧困層、山岳民族、外国人労働者の結核患者が通院にかかる交通費、生活費の補助を受け、最後まで結核の治療を受けることができました。中には重篤患者で命を落とした方もいますが、女性ボランティアからの思いやりを受け、人間としての尊厳を保った死でした。

女性ボランティアに今後どれだけ活動が続けるのかと聞くと、「できなくなるまで」との返答がありました。わたしの息が止まるまで結核ボランティアを続ける、これは今年の結核デーのテーマである「ストップ結核…私が生きている間に」に一致しているのではないのでしょうか。

