

## Title

Challenges to primary healthcare services in the management of non-communicable diseases in marginalized populations on the Thailand-Myanmar border: a pilot survey

## Short title

Suboptimal NCD care for a marginalised population

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## **Abstract**

Non-communicable diseases (NCDs) are emerging rapidly. This manuscript reports on a pilot survey of NCDs at a primary healthcare level in a marginalised migrant population on the Thailand-Myanmar border in the face of declining rates of malaria.

A retrospective audit of routine clinic (2004–2016) and NCD patient survey data (2014–2016) was conducted. The length of follow-up was assessed by Kaplan-Meier analysis.

From July 2014 to July 2016, 238 migrant patients were on the NCD register. Hypertension (n=80) and diabetes mellitus (n=51) were the most common diagnoses. After the first consultation, 41% (95% confidence interval: 35–47%) were lost to follow-up by 30 days. NCD retention rates were low: 50% of registered patients were lost to follow-up by 80 (95%CI: 49–132) days.

After this survey, a novel low-cost insurance scheme for the migrant community has been launched in this area. Development of new schemes involving patients, healthcare providers and funding support are required for improved and sustainable NCD care for marginalised populations.

## **Introduction**

Non-communicable diseases (NCDs) are an emerging concern globally. In South East Asia, 64% of total deaths<sup>1</sup> and 58% of total disability-adjusted life years<sup>2</sup> are estimated to be due to NCDs, and these figures are expected to increase. In addition to public health interventions, primary healthcare providers play a key role in the management and control of these morbidities.<sup>3</sup>

Very little attention has been devoted to the management of NCDs in displaced populations particularly in conflict and post-conflict settings except in acute surgical/trauma emergency situations.<sup>4, 5</sup> Shoklo Malaria Research Unit (SMRU) is an organisation that integrates humanitarian medical aid and medical research in rural areas at the north-western border of Thailand. SMRU's clinics have provided primary healthcare services to refugees since 1986 and migrants since 1996, with the majority of the patient population coming from Myanmar.

Stable, limited data collection about outpatient visits provides an opportunity to assess the epidemiological transition as the burden of disease shifts from primarily acute infectious diseases towards NCDs in this area. The aim of this survey was to describe NCDs from the provider's perspective in terms of caseload and follow-up patterns at the primary healthcare level in an unstable, marginalised, migrant population.

## Methods

SMRU is located in Tak province, Thailand and operates primary care clinics along the border. There are an estimated 104,000 refugees from Myanmar living in camps along the border.<sup>6</sup> In addition, there are estimated 235,820 migrants from Myanmar working at the border.<sup>7</sup>

The audit took place at the Wang Pha (WPA) clinic, which is located on the Thai bank of the Moei River. Most of the migrants in this rural area work in agriculture. The population is mostly of Karen or Burman ethnicity. WPA clinic consists of departments providing care for outpatients (OPD), inpatients, neonates, and pregnant women at antenatal care and during childbirth. Locally trained medical staff (hereinafter referred to as medics) and midwives are stationed in each unit (one or two for OPD) during the daytime, and two medics are in charge of inpatient and emergency OPD care at night, thus running the clinics for 24 hours. In this setting, nurses usually obtain three months of theory and three to six months practical training, and medics have six to twelve months of theory and one year of supervised practice. A medically qualified doctor supports staff round-the-clock.

### NCD registration and management

Any diseases needing chronic care resulted in registration and included metabolic disorders as well as congenital disease or nephrotic syndrome in children. Tuberculosis and HIV were treated in a dedicated clinic nearby, and thus not included. Due to difficulty in obtaining drugs for palliative or curative care, patients with cancer were neither registered nor followed.

On each visit, patients received a physical examination, and vital signs were assessed by nurses or medics. Urine dipstick and sediment, and blood glucose measurement were also available. Budget constraints permitted specialised tests such as blood biochemistry or thyroid function tests to assist clinical care on a limited basis. The medics diagnosed and managed patients according to The Burmese Border Guidelines 8 under the supervision of doctors. Medication for NCDs was supplied for a maximum of one month at each visit. All medical services were provided free of charge, but expensive medications such as insulin were rarely prescribed because of constraints including cost, access and auxiliary items (such as ice box, syringes and needles). From July 2014, follow-up was discussed with all NCD OPD patients, and the expected and actual dates of clinic visits were recorded in a logbook.

Anonymized data were extracted from routine monthly reports of SMRU OPD activity, which included age group, gender, and diagnosis. Acute and chronic disease presentations recorded in the registers from 2004 to 2016 at WPA clinic were calculated. From the NCD registry (between July 2014 and July 2016), age, sex, diagnosis, date of first and last consultation and recent management were extracted. Patients were regarded as clinically stable if there was no change in the prescribed medication in the last three months.

STATA 14.2 MP (Stata Corp, Texas, USA) was used for the descriptive analyses. For assessing the duration of follow-up, Kaplan-Meier estimates were calculated

using loss to follow-up as the outcome. Patients were regarded as lost to follow-up on the last date seen if they did not come at least once in the last three months of the audit period. The patients who were actively followed until the end of audit period, confirmed dead or referred out were regarded as being censored for this analysis on the last date seen.

### **Ethical considerations**

No ethical approval was sought for this retrospective audit of previously collected routine clinical data which were extracted fully anonymized and could not have been traced back to individual patient by the researchers.

### **Results**

Epidemiological transition from malaria to non-malaria diseases

WPA clinic has completed approximately 10,000 outpatient visits per year since 2005 and a dramatic reduction in malaria cases has been observed from 2009, while non-malaria outpatients' visits have remained high (Fig 1).

There were 238 patients registered on the NCD logbook between July 2014 and July 2016. Complete logbook data entry was available for 97.5% (232/238) of patients with the six incomplete entries excluded from the analysis. The median age of registered patients was 43 years (inter-quartile range [IQR] 27–53) and 156 (67%) were female. Diagnostic groups included hypertension (80, 34%), diabetes mellitus (51, 22%), asthma (29, 13%), thyroid diseases (28, 12%), nephrotic syndrome (16, 7%), epilepsy (15, 6%), chronic heart disease (14, 6%), chronic obstructive pulmonary disease (7, 3%) and others (27, 12%). Chronic kidney or liver diseases were probably underestimated as routine kidney or liver function tests were not performed. There were no confirmed deaths, and there was one case with diabetes mellitus referred to a Thai hospital.

After an initial two-month period of registration, the median number of patients who were newly diagnosed with NCDs was 7/month (IQR 5–13). There was a seasonal variation (high in June–September) but there was no overall trend suggesting an increase in newly diagnosed NCD patients over time (Fig 2). However, the monthly total number of patients who were actually followed up increased steadily from 33 in August 2014 to 74 in June 2016. This occurred despite the high rate of loss to follow-up described below.

After the first consultation, 41% (95% confidence interval [CI]: 35–47%) were lost to follow-up by 30 days. NCD retention rates were low; 50% of registered patients were lost to follow-up by 80 (95%CI: 49–132) days. The length of 50% follow-up was particularly short in patients with a diagnosis of solely hypertension diagnosis, compared to other diagnostic groups: 54 (95% CI: 18–101) days and 112 (95% CI: 49–218) days, respectively.

In July 2016, 83 patients had been followed up at least once in the previous three months. Active management was needed by 56 (67%) with changes in their treatment from the previous three months. Irregular (but not timetabled) attendance was seen in 31 (37%). Assuming that all who were enrolled in NCD management but lost to follow-up were still alive (and excluding one patient

referred to another hospital) only 23% (52/231) of this cohort of patients were attending their scheduled visits at the end of the survey period.

## **Discussion**

Severe falciparum malaria is associated with significant mortality but one of the keys to reducing this on the Thailand-Myanmar border has been early diagnosis and treatment of uncomplicated malaria at the primary health care service level. It is not surprising that this rural and limited-resource setting has concentrated on acute febrile and non-febrile infectious disease care. Although acute infectious diseases are decreasing, ongoing vigilance is required, and patients naturally turn to primary health care to manage the double burden of infectious diseases and NCDs.

In our pilot survey, two-thirds of NCD patients were lost to follow-up over a 25-month surveillance period. For the remaining one third who came to follow-up, care was provided free but was limited in scope. Many patients failed to come to scheduled appointments, and intermittent unscheduled visits were common. This occurred even when staff were actively involved patients in choosing the subsequent follow-up appointments. This may in part be affected by seasonal agricultural work of the migrant population, as reflected in rainy season attendance rates (Fig 2), as well as the unpredictable nature of intermittent employment.

Although medication cost is not likely to be the main reason for low follow-up rate as the medical service is provided free of charge, the real cost for patients attending follow-up visits can be substantial when direct costs (e.g. transportation costs and check-point fees) or other indirect costs (e.g. lost wages and the other family members' time) are factored in.<sup>9</sup> A missed day of work could significantly affect a family's weekly income.

To improve follow-up and outcomes, self-engagement in interventions may be key for NCD care.<sup>10</sup> Lack of knowledge about disease owing to limited basic health education must reduce long-term adherence.<sup>11</sup> In this region, knowledge of diseases, especially NCDs, was reported to be low: more than half considered NCDs (i.e. namely diabetes, hypertension and COPD) to be curable (like acute infectious diseases).<sup>12</sup> This means that ensuring appropriate understanding of disease is important to improve follow-up, especially for less drastically symptomatic diseases such as hypertension.<sup>11</sup> This may also explain the contrasting higher follow-up of patients with tuberculosis ( $\geq 95\%$  for 6-12 months, unpublished data), but these patients were supported with transport costs, counselling on adherence and treatment completion as part of their overall package.

As conflict in the Thai-Myanmar border region has been ongoing for decades, basic education of most patients presenting to SMRU clinics with NCDs has been fragmented. Achieving basic understanding will require dedicated staff time and development of context-appropriate counselling materials in the languages which patients use. At SMRU, this is even more challenging because of the three languages commonly spoken, staff may only be fluent in two.

An effective programme to address health needs for this marginalised border population needs to include intentional and expanded programming, instead of ad-hoc treatment of disease using a strained acute-care model. An underlying theme behind most challenges to improve care and outcome is funding shortfalls. Resource constraints affect staff and patient education and motivation, quality of clinical care (available diagnostic tests, treatment and referral options), and outreach activities.

At the country level, the Asia Pacific Observatory on Public Health Systems and Policies reported in 2014 that only 1% of the population in Myanmar was covered by the Social Security Scheme, and 79% of total health expenditure was paid by the household.<sup>13</sup> Furthermore, in border areas access to the national health system is often restricted<sup>5</sup> and healthcare systems are more fragmented. At SMRU, the decision of referral to the well-resourced but increasingly costly Thai healthcare system forces providers to make impossible choices balancing the wellbeing of individual patients with the long-term sustainability of local primary health care services.

The retrospective nature and small number of NCD cases in this analysis limit conclusions. Important information such as employment, distance to the clinic, education level, socio-economic status, or alternative abode/address was not available. This type of data would have been useful to determine risk factors for lost to follow-up. Results in this migrating population may not be directly generalisable to other migrant groups in border areas, though some overarching themes (e.g. lack of financial scheme for healthcare and difficulty in patient education on NCDs) transcend the local setting. With displaced persons on both the east and west border areas of Myanmar, migrant numbers are increasing and provision of their health remains precarious.

In this small pilot report OPD visits appear consistently high but a more careful analysis realizes care of NCDs is sub-optimal. Challenges at primary healthcare level occur where decreasing burden of infectious diseases conflicts with increases in NCDs.

#### Footnote:

After 2016, taking into account the funding situation, and incapability of providing long-term good quality NCD management, SMRU chose to cease NCD case management. Most patients were referred to Mae Tao Clinic, now the only major provider of free NCD care in this community. Meanwhile, SMRU and Mae Tao Clinic have collaborated with Dreamlopmments ([www.dreamlopmments.com](http://www.dreamlopmments.com)), a non-profit organization working to provide low-cost insurance for the migrant community, in hopes of finding a sustainable pathway to link unregistered migrant workers living with NCDs in this area with affordable quality health care. This insurance scheme has a specific program for NCD care and would ideally expand to provide case management for NCD clients in the future.

#### List of abbreviations

IQR: inter-quartile range; NCDs: non-communicable diseases; OPD: outpatient department; SMRU: Shoklo Malaria Research Unit; WPA: Wang Pha.

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#### Declarations of interest

The authors declare that there is no conflict of interest.

#### References

1. World Health Organization. Projections of mortality and causes of death, 2015 and 2030. Geneva: World Health Organization, 2013.
2. World Health Organization. Projections of mortality and burden of disease, 2004-2030. Geneva: World Health Organization, 2008.
3. Dans A, Ng N, Varghese C, Tai ES, Firestone R and Bonita R. The rise of chronic non-communicable diseases in southeast Asia: time for action. *Lancet*. 2011; 377: 680-9.
4. Roberts B, Patel P and McKee M. Noncommunicable diseases and post-conflict countries. *Bull World Health Organ*. 2012; 90: 2.
5. Spiegel PB, Checchi F, Colombo S and Paik E. Health-care needs of people affected by conflict: future trends and changing frameworks. *Lancet*. 2010; 375: 341-5.
6. The Border Consortium. The Border Consortium Annual Report January - December 2015, <http://www.theborderconsortium.org/resources/key-resources/> (2016, accessed 10 October 2016).
7. Archavanitkul K. Interesting Figure: The Ten Most Populated Provinces of Migrants in Thailand from Myanmar, Cambodia, and Lao PDR, 2013. In: Mahidol Migration Center, (ed.). The newsletter MMC. Bangkok: Institute for Population and Social Research, Mahidol University, 2014.

8. Shoklo Malaria Research Unit. The Burmese Border Clinical Guidelines. Mae Sot, Tak, Thailand: Shoklo Malaria Research Unit, [http://www.shoklo-unit.com/sites/default/files/bbg\\_medical\\_guidelines\\_19apr2016.pdf](http://www.shoklo-unit.com/sites/default/files/bbg_medical_guidelines_19apr2016.pdf) (2016, accessed 10 October 2016).
9. Tschirhart N, Nosten F and Foster AM. Access to free or low-cost tuberculosis treatment for migrants and refugees along the Thailand-Myanmar border in Tak province, Thailand. *Int J Equity Health*. 2016; 15: 100.
10. Yadav UN, Hosseinzadeh H and Baral KP. Self-management and patient activation in COPD patients: An evidence summary of randomized controlled trials. *Clin Epidemiol Glob Health*. 2017. DOI: 10.1016/j.cegh.2017.10.004.
11. Levitt NS, Puoane T, Denman CA, et al. Referral outcomes of individuals identified at high risk of cardiovascular disease by community health workers in Bangladesh, Guatemala, Mexico, and South Africa. *Glob Health Action*. 2015; 8: 26318.
12. Lorga T, Aung MN, Naunboonruang P, Junlapeeya P and Payaprom A. Knowledge of communicable and noncommunicable diseases among Karen ethnic high school students in rural Thasongyang, the far northwest of Thailand. *Int J Gen Med*. 2013; 6: 519-26.
13. World Health Organization. The Republic of the Union of Myanmar health system review. Manila: World Health Organization, Regional Office for the Western Pacific, 2014.

#### Figure Legends

Figure 1: Annual total number of malaria and non-malaria outpatients at Wang Pha clinic (2004–2015).

Figure 2: Number of outpatients with non-communicable diseases (NCDs) per month at Wang Pha clinic (Aug-2014 to Jun-2016): bar - represents newly diagnosed NCD outpatients, line - actual NCD patients followed.