# Socio-demographic impact of antiretroviral treatments in Northern Thailand

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#### Introduction

The World Health Organization (WHO)/UNAIDS estimated that in 2005, 40.3 million people were living with HIV worldwide, yet only a fraction have access to the life saving but costly antiretroviral treatments needed<sup>1</sup>. At the end of 2003, access to antiretroviral (ARV) treatments in developing countries began to expand and an estimated 250 000 to 350 000 deaths have since been averted due to the scale up of treatments. Although the objective of the WHO "3 by 5" initiative –Treating 3 million patients by 2005—was not reached, an unprecedented effort has been made by international agencies, governments and NGOs in the fight against AIDS<sup>2</sup>.

As more countries initiate and further scale up antiretroviral treatment programs, the WHO strongly recommends operational research to analyze the strengths and weaknesses of these programs taking into account equity in access, the impact on prevention, risks behaviors and discriminatory attitudes, the impact on the health systems capacity and performance, as well as evaluation of program costs relative to their benefits.

## Thailand socio-demographic situation

The Thai population was estimated to be 63.8 million in 2004. In the last 3 decades, Thailand experienced significant decline in both mortality and fertility rates. In the 2000 census, the annual population growth rate was estimated as 1.05%. The total fertility ratio has decreased significantly from 6.3 children per woman in the mid-1960s to 1.8 in 2000, with the north of the country having the lowest fertility ratio of 1.5, and an average household size of 3.4 people<sup>3</sup>. The age-sex structure of the Thai population is rapidly changing from a broad-based to a narrow based pyramid with an increasing majority of the population aging. Northern Thailand, the region where this antiretroviral treatment program was implemented, is a largely rural area, with the majority of the working population engaged in farm-related activities, and the remainder engaged in small trade and services, most of which are tourism related. Apart from few industrial zones, manufacturing industries have had limited development in this region.

## Thailand situation with regards to HIV

Among all Asian countries, Thailand was one of the first and hardest hit by the HIV pandemic. The epidemic first developed among intravenous drug users, and then among commercial sex workers and theirs clients<sup>4</sup>. As the epidemic matured, heterosexual transmission became the major route of infection in the general population<sup>5</sup>. The Royal Thai government responded quickly to the HIV/AIDS epidemic and initiated a multi-sectoral AIDS program in 1987<sup>6</sup>. Over one million persons in Thailand have been infected with HIV, of whom approximately 551,000 have died7. In 2004, 540,000 persons were estimated to be living with HIV/AIDS7 in Thailand. The north of Thailand has been and continues to be the most affected region with HIV prevalence rates consistently higher than other regions<sup>6</sup>.

The National AIDS Program to prevent the spread of HIV in the general population achieved some unique successes through the 100% condom campaigns. The impact was reflected in the reduced prevalence of HIV among key representatives of the general population, such as military conscripts where the prevalence fell from 4% in 1993 to 1.3% in 1999, and in pregnant women attending antenatal clinics the prevalence decreased from 2.7% in 1995, to 1.08% in 2007<sup>9</sup>.

In spite of these efforts, between 1990 and 2000, there were an increasing number of symptomatic HIV infected patients in need of immediate care, increasing the AIDS-related demands at the hospitals, particularly in the north<sup>8</sup>. The impact of the epidemic in terms of stigma and discrimination was well documented<sup>10</sup> in this period, before wide access to antiretroviral treatment.

#### Antiretroviral access in Thailand

Following the government's highly efficient prevention program, Thai health policy makers worked towards scaling up access to antiretroviral treatments for HIV infected adults and children, while trying to maintain financial balance within the government health budget.

National provision of antiretroviral treatments began at the end of 2000, with the pilot Access To Care (ATC) Treatment program launched by the AIDS Division of the MoPH. The program provided antiretroviral treatments, targeting HIV infected pregnant women in need of treatment after delivery. The program was piloted in key provincial and district hospitals in some of the most affected regions, many of which were in northern Thailand. In October 2003, the Ministry of Public Health scaled up provisions of treatment to hospitals throughout the country with the National Access to Antiretroviral Program for People Living with HIV/AIDS (NAPHA), co-financed by the Global Fund to fight AIDS, Tuberculosis and Malaria (GFATM). As of February 2005, 52,593 patients in Thailand had received antiretrovirals through the NAPHA program, and an additional 8,000 were estimated to be receiving ARV treatment through the Social Security Scheme (private sector's health insurance)<sup>11</sup>. The NAPHA program has now been integrated into the Universal Health Coverage System, which incorporated free provision of antiretroviral treatments in October 2005, and is expected to further expand access to antiretroviral treatments to a total of 80,000 patients by the end of 2006.

## The PHPT-Oxfam Program

Within the national antiretroviral treatment scale up efforts, a clinical research consortium "Programs for HIV Prevention and Treatment" (PHPT) initiated one of the first pilot programs for community based antiretroviral treatment in Thailand, from January 2002, with support of an international NGO, Oxfam GB<sup>12</sup>. At that time, access to antiretroviral treatments at community hospitals was very limited due to their high costs and the lack of experience of the health care providers. The objective of the program was to demonstrate the feasibility of provision of comprehensive high quality HIV care including antiretroviral treatment in the community hospital setting, through capacity building of the health care system and personnel and involvement of persons living with HIV/AIDS and the community in program implementation.

The PHPT-Oxfam program was implemented in four community hospitals and one regional hospital in the Chiang Mai Province for five years from 2002 to 2007, after which it was successfully integrated into the national health system. During the five years, data on clinical and biological outcomes were collected, providing an ideal basis from which to collect additional empirical data on the socio-demographic and economic impact of antiretroviral treatments. A thorough evaluation of this program may also provide important data for guidance and recommendations for further scaling up of antiretroviral programs at the regional and national level.

## **Objectives**

The overall aim of this research project is to study the socio-demographic and economic impact of access to antiretroviral therapy on the lives of the patients, their families and communities, as well as its impact on the health care delivery system within a community heavily affected by the HIV epidemic in northern Thailand.

#### Methods

HIV/AIDS and its treatment with antiretrovirals have consequences beyond the individual patient level, it affects the family, community and the health care system, therefore it is important to gather information of the impact at these multiple levels of society. We have designed a data collection system which combines quantitative surveys for patients receiving antiretroviral treatment, and qualitative interviews of different affected groups such as PLWHA, family members/care-givers, health care workers, community representatives and HIV affected or infected children.

#### Ouantitative survey in the hospital setting

**Population:** All adult patients (approximately 500) receiving antiretrovirals in the four community hospitals, through the PHPT-Oxfam program, the national program or through other coverage schemes will be proposed to participate in the study. If consenting, participants will be provided an appointment for the life-event interview.

While the adults receiving antiretroviral treatments in these 4 community hospitals may not be representative of the whole population of HIV-infected patients in Thailand, they are representative of the majority of patients in the general population in rural or sub-urban communities in northern Thailand who are aware of their HIV status, who need treatment, and, as Thai citizens are eligible to treatment under the public health system<sup>11</sup>.

## The Life-event history survey

The classical approach to analyze the impact of antiretrovirals on the lives of the individuals would be to follow prospectively a population of HIV-infected individuals and assess the changes in their situation by interviewing them at different time points: before treatment initiation, and regularly thereafter (every 6 months or every year).

However, this would require a huge logistical apparatus and would not resolve the problem of attrition related to lost-to-follow-up. It also implies support of field work logistics over a long duration as the follow-up period need to be long enough to be informative. The alternative approach, chosen here, is a retrospective life-event history survey where participants currently on treatment are interviewed about their history (residence, family, education, activity, migration, health, for example). Using this methodology, allows comparison of the lives of patients before/after HIV infection, and before/after antiretroviral treatment. Recall bias which would be a limitation of this approach, is less of an issue in this setting as the participants' perception of changes in their life is more important than the events themselves<sup>13</sup>. The fact that patients who died cannot be included in the survey is an inherent limitation of this approach. Yet, it will be counterbalanced by our capacity to include patients who voluntarily stopped their treatment, who would have been at greater risk of lost to follow up in prospective studies.

Issues to be addressed in the life-event surveys include:

- 1) Socio-demographic situation
  - Family: previous and current marital status, children, parents, prospect for the future in terms of children; Education; Residential history; Work history; Social network: previous and current
- 2) Economic situation
  - Financial status: previous and current, including income, assets and debts; Sources of financial support; Health Care Coverage; Health care expenditures: previous and current
- 3) Health history
  - Health status; Disease history: assumed date of debut, date of diagnosis, occurrence of symptoms, hospitalizations; CD4 and viral load: before antiretroviral treatment and at present; Treatment history: date of initiation, type of treatment, change of treatment over time, reasons for change; Experience with treatments: Adherence, side effects, toxicity; Adherence to treatment, Disclosure history
- 4) Quality of the interaction with health care providers
- 5) Care-giver support: who, how
- 6) Overall appreciation of happiness throughout different periods of life; Life crises (financial, health, love, domestic violence, accidents, etc.)

## **Qualitative surveys**

### **Target Populations and approach**

Exploratory qualitative interviews will be performed with some adult patients receiving antiretrovirals or those who have stopped voluntarily their treatment before launching the quantitative survey to help in the design of the life-event questionnaire.

A second set of qualitative thematic interviews will be performed in parallel to the quantitative surveys among the patients receiving antiretroviral treaments:

- Family members, Care/givers of HIV+ patients (adults or children)
- Health care workers taking care of HIV+ patients
- **Community representatives**: members of PLWHA groups, community based associations, religious groups, local leaders, etc.
- HIV-infected children on antiretroviral treatments > 10 years old and aware of their HIV status.

## **Expected Results**

Building upon the valuable clinical data already gathered for over 5 years of the PHPT-Oxfam program, this project will provide the contextual information (socio-demographic, quality of life, health attitudes and perception, and economic data) to better understand the impact of antiretroviral community based programs. Our results are expected to yield insights on the multi-dimensional impact of antiretroviral treatment provision, beyond the individual health level, to the levels of the family, network adjustments, and the community.

This evaluation aims to inform policy makers and contribute to current debates regarding access to antiretroviral treatments in resource limited settings. By conducting socio-demographic and socio-economic evaluations we hope to document the wide-ranging consequences of provision of antiretroviral treatments, and subsequently highlight limitations of one dimensional evaluation in informing decision makers on the scope of costs and benefits of expanding access to antiretroviral treatments for affected communities and countries.

At the conference, we will present an evaluation of the survey procedure, an overview of the first results, with a special focus on the evolution of discrimination patterns prior and post-antiretroviral treatments.

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