Home and Community-based Care for Persons Living with HIV and AIDS in Thailand:

Lessons Learned and Future Prospects

Synthesized by:

Professor Bhassorn Limanonda, Ph.D.

College of Population Studies,

Chulalongkorn University

Home and Community-based Care for Persons Living with HIV and AIDS in Thailand: Lessons Learned and Future Prospects

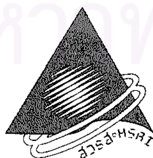
Synthesized by:

Professor Bhassorn Limanonda, Ph.D.

College of Population Studies,

Chulalongkorn University

สถาบันวิทยบริการ
จุฬาลงกรณ์มหาวิทยาลัย



Home and Community-based Care for Persons Living with HIV and AIDS in Thailand: Lessons Learned and Future Prospects

Synthesized by Bhassorn Limanonda, Ph.D.

Published by:
Health Systems Research Institute (HSRI)
c/o 5th Floor, 3rd Building, Mental Health Department,
Ministry of Public Health, Tivanond Road, Nonthaburi 11000,
Thailand
Tel. (662) 951-1286-93 Fax. (662) 951-1295
http://www.hsri.or.th e-mail: hsri@hsrint.hsri.or.th

First published: December 2001
© 2001

National Library of Thailand
Cataloging-in-Publication Data
Bhassorn Limanonda.
Home and Community-based Care for Persons Living with HIV and AIDS in Thailand: Lessons Learned and Future Prospects. --Nonthaburi: Helth Systems Research Institute, 2001.
40 p.
1. AIDS (Disease)--Patients--Care of the sick. I. Health Systems Research Institute. II. Title.
362.1969792
ISBN 974-299-073-5

Designed and printed in Thailand by:
Desire Co., Ltd.

Contents

Research Papers' Contributors	iv
Abstract	1
Background	2
Objectives and Scope of the Paper	4
The Expected Outcome	6
Home and Community-Based Care: Basic Concept and Definition	7
HIV/AIDS Epidemic: National Situation and Responses	11
HIV/AIDS Epidemic: Regional Situation	13
Home and Community-Based Care System: Regional Strategies Development	16
Key Mechanisms to Sustain Home and Community-Based Care System	22
Conclusion: Lessons Learned and Future Prospects	32
Issues that Need to be Reconsidered	35
References	40

สถาบันวิทยบริการ
จุฬาลงกรณ์มหาวิทยาลัย

Research Papers' Contributors

The North:

Somsak Supawitkul, M.D.

Chiang Rai Provincial Health Office

Pikul Nantachaipan, Ph.D.

Nursing Faculty, Chiang Mai University

Pisit Sae Tang

Enhancing Care Initiative (ECI), Thailand,

Nursing Faculty, Chiang Mai University

Niwat Suwanphatthana

AIDS Network Development Foundation, North Office

The Central

Assoc. Prof. Sutheera Hoontrakul

Faculty of Nursing, Mahidol University, Bangkok

Assistant Prof. Pensri Kaweevongprasert, Ph.D.

Faculty of Medicine, Thammasat University (Rangsit Campus), Pathum Thani

สถาบันวิทยบริการ
จุฬาลงกรณ์มหาวิทยาลัย

The South

Assistant Prof. Praneed Songwathana, Ph.D.

Faculty of Nursing, Prince of Songkhla University,

Hat Yai, Songkhla

Sirilak Chanderma

Head, Nursing Department, Badang Bezar Hospital

Sadoa District, Songkhla Hospital

Lecturer Quantar Baltip

Faculty of Nursing, Prince of Songkhla University,

Hat Yai, Songkhla

The Northeast

Assistant Prof. Bumpenchit Sangchart, Ph.D.

Faculty of Nursing,

Khon Kaen University, Khon Kaen

Captain Wasinee Wisesrith

Docterate Student, Faculty of Nursing,

Khon Kaen University, Khon Kaen

Synthesized by:

Professor Bhassorn Limanonda, Ph.D.

College of Population Studies,

Chulalongkorn University, Bangkok

สถาบันวิทยบริการ

จุฬาลงกรณ์มหาวิทยาลัย

Home and Community-based Care for Persons Living with HIV and AIDS in Thailand: Lessons Learned and Future Prospects

Abstract

The paper reviewed and synthesized strategies and approaches of home and community-based care for persons living with HIV/AIDS practiced in four regions of Thailand. The Northern region, where the epidemic has severely struck for almost two decades, has well developed various strategies and innovative approaches for caring the infected and sick persons. These strategies were followed and partly adapted to suit the existing socio-economic and cultural context of other three regions. Program evaluation in the four regions identified four important mechanisms which could contribute to the success or failure of the home and community-based care system. They include PWHA's willingness to reveal themselves, acceptance and understanding of family and community; well-equipped NGOs; and continued support and commitment of the GOs. Apart from these four mechanisms, socio-economic and cultural context existed in each region also played vital role in the

operation and management of caring provision system.

Under the resources constraints, increasing number of infected and AIDS patients, and greater demand for services, the existing home and community-based care approaches need to be holistically reviewed for improvement and effective use in the future. The on-going programs and activities need to be closely monitored and continuously evaluated for their efficacy and efficiency in dealing with the epidemic and its impacts.

Background

The concept of home and community-based care strategies in Thailand has received serious consideration since early 1990's when the number of persons with HIV/AIDS (PWHAs) have dramatically increased, coupled with limitation of resources and health personnel as well as less availability of health care facilities. These circumstances have driven the Thai government to review the existing health care service for PWHAs as a whole, the capacity in providing adequate services while searching for the alternatives that could efficiently serve needs and improve PWHAs' quality of life. Among many approaches, home and community-based care has been initiated as the most suitable strategy to deal with above mentioned problems. This strategy is meant to maximize utilization of existing and available resources within the community while family and community's participation is taken as basic components to provide care to PWHAs. However, it is recognized that in operating home and community-based care system, coordination and continued support from

multisectoral such as governmental, non-governmental, and charitable organizations, religious institution and community-based organizations should also be activated (AIDS Division, 1999).

The home and community-based care approaches have been first initiated and implemented in the Northern region of Thailand where the epidemic was most severe, as new strategies for caring of PWHAs through a local base: family and community. While many of home and community-based care programs and activities were initiated by the government organizations with the additional support from the non-governmental organizations, family and community have become based-care units shouldering much more responsibilities than before. Later, the approaches invented and implemented in the North have become strategies to be followed by other three regions where the epidemic has struck in much later period. However, program evaluation results from various sources indicated that during the past decades, the implementation and management of home and community-based care in the four regions have operated with some difficulties. Many NGOs have disappeared from the scene due to limitation of resources; budget, manpower, lack of qualified and well-trained personnel, financial mismanagement, lack of long-term workplan etc. On the other hand, the GOs have played more passive role rather than the active roles in implementing the strategies. More seriously, families and communities in many parts of the country, have not yet been well prepared to shoulder the new responsibility in caring of the PWHAs. In many communities, the negative attitude toward and discrimination against

the PWHAs has been still very strong. The PWHAs who have been rejected by their families and communities, have to instead form up their own group (self-help group) or network to care for each other and protect their rights with regard to prejudice and discrimination. Among many hundreds of self-help groups and networks that were created in the past years, many of them have been well developed and empowered themselves to become interest groups who could negotiate with other groups for support. On the other hand, many PWHA self-help groups and network have weaken and disappeared with various reasons.

All these difficulties mentioned above should be viewed as 'lessons learned' and need to be carefully assessed. The in-depth understanding of these whole issues and ability to identify the obstacles will, hopefully lead to the improvement of or the 'better' approaches for future use.

Objectives and Scope of the Paper

This paper reviews and synthesizes home and community-based care strategies invented for PWHAs, and have been practiced in four regions of Thailand. Experiences of the Northern region will be used as a reference since this region has developed and implemented these approaches long before other regions. Problems involved in the developmental process of home and community-based care strategies will be identified and discussed. Facilitators or obstacles of the operation of mechanisms vital to the sustainability of this new dimension of caring system will also be discussed. In order to reach these objectives, the

paper will first review 4 following issues:

1. Basic concepts and definition of home or family and community-based care

2. Situation on HIV/AIDS epidemic (magnitude and degree of problems) in each region that leads to the initiation and development of home and community-based care strategies. In relation to this, the paper will also review knowledge, understandings and attitudes of family and community on HIV/AIDS that lead to acceptance or rejection of PWHAs. The paper will, in addition assess efforts and resources from both local and outside organizations, invested in programs and activities to handle problems.

3. In reviewing home and community-based care strategies implemented in four regions, following aspects will be discussed, or if possible, will be compared.

   a. roles of family, community, religious institution, GOs and NGOs as well as other social network in providing care and support for PWHAs;
   b. similarities and differences of approaches used in each region;
   c. potentialities and coping ability of family and community in handling problems;
   d. determinants of the chosen strategies/approaches (ie. economic, social, cultural, local wisdom, beliefs and values);
   e. mechanisms contributing to the success or failure of the development and implementation of home and community-based care system.

4. The paper will, in addition, assess the availability and existence of body of knowledge on home and community-based care, which built up upon research findings carried out in the past years, and to identify knowledge gaps that need to be filled up for future use.

The Expected Outcome

The paper will finally **synthesize** all information obtained from the reviews of the above 4 aspects to provide the overall picture of home and community-based care system for PWHAs in Thailand. The synthesis will focus on comparative of the HIV/AIDS epidemic situations in four regions that have led to the development of home and community-based care strategies used in each locality. The synthesis will also assess the role and significance of various mechanisms in driving the system to operate effectively. If not, what are the problems?

The experiences both right and wrong, success and failure obtained through the investigation in four regions should provide some directive guidance for every parties involved to pay more attention to these identified problems and plan ahead what should be improved for the 'new' or 'better' home and community-based care strategies and be most beneficial for PWHAs in Thailand. If possible, these experiences could also be valuable lessons learned for many other societies as well.

Home and Community-Based Care: Basic Concept and Definition

Since past decade, the idea of using home and community-based care approach as an important strategy for AIDS prevention and care has been widely accepted in many societies. This is because the burden of long-term care for large pool of PWHAs seemed to grow beyond the capacity of the government health care system to cope with the upsurge patients. In this situation, family and community are considered to be most important basic social units to share responsibilities in handling the consequences, and care for their own members at the family and the community level. At the same time, family and community should develop their own strength in promoting understanding and compassion for PWHAs. (Rau, 1994).

According to a definition given by the World Health Organization, 'care' should cover 4 important dimensions; that is medical care, nursing care, counseling service and social support. It is expected that these four dimensions could be best carried out at home and in the community. In a more specific meaning, ***Family or home-based care*** refers to the provision of care for PWHAs at home where family members taking a role of care-taker and be responsible for the task. The family or home-based care has few advantages, as follows, over care provided by other systems.

a) basic and simple care could be provided at home;
b) mentally, PWHAs will feel better when surrounded by family members;

c) less burden for health personnel in caring for patients with chronic symptoms;
d) home care generally costs less in comparison of hospital care;
e) at the terminal stage, the patient prefers to be at home with their family members;
f) strengthens family tie and better relationship between PWHAs and the family;
g) encourages the family to take role and responsibility in caring of PWHAs.

On the other hand, ***Community-based care***, by definition, is more complicated and is not as clear cut as that of family or home-based care. The community, physically could refers to a physical setting of a locality, or a body of people living in the same place, or otherwise, the community could refers to relationship among group members who either live within or outside boundary of the physical setting. Recently, the new concept 'civil society' has been introduced as a tool to solve AIDS-related problems and care provision for PWHAs. The 'civil society' refers to the ideal community where the relationship among members is built upon, share common objectives and work out together to solve problems that pose threats to the well-being of its members.

It is important to understand that the initiation of home and community-based care is not to totally transfer or to impose burden and responsibilities to family members and community in caring of PWHAs. It is, however the Government's attempt to encourage these two basic social components to participate in

the caring process, and to contribute morale support which is most important for physical and mental health of PWHAs. It also will strengthen the capacity of the family and community in handling problems related to AIDS more appropriately through their own local wisdom. However, experiences from many places showed that the effectiveness of community-based care program much depends on many other factors. They include the readiness of the family and the community to cope with their own problems (such as burden of care provision, cost for caring, medication, discrimination against PWHAs, death and psychological issues), regular support and supervision from health care providers at local level, knowledge and attitudes of community members towards AIDS. To strengthen the community to cope and handle the burdens of care, the family and community need assistance from all parties involved (Coglan, Kabandu and Musungu, 1994).

In the home and community-based care system, 4 basic elements are identified to be very important mechanisms for the effective operation of the system. These four mechanisms include;

◆ **The State or the Governmental Organization (GOs).** According to Moodie and Aboagye-Kwarteng (1993: 1545-6), the role of the national government should be that of a facilitator and catalyst in getting a variety of responses from various groups. They must act to create an environment that increases the possibilities for behavioral change through financial, political and legislative support for the community responses. In the home and community-based care system, the State should, therefore be the first mechanism that set up the national policy

concerning the control, prevention, care, and support as well as budget allocation necessary for the development and operation of strategies.

♦ **The Non-Governmental Organizations (NGOs)** is the second mechanism which coordinate, and play the supplementing role to fill up gaps where the government organizations are unable to fulfill in the process of health care service provision.

♦ **The Community and the Family** is the third mechanism in the home and community-based care system. Various community-based organizations could play a critical role in responding the AIDS-related problems. Many communities, at present need to be strengthened to handle the AIDS-related problems existed in their own locality. Participation of community in caring of their own members means greatly for the survival of the system. On the other hand, ***the family*** is the basic but most important mechanism in the system of care provision for PWHAs. However, the negative attitudes and irrational fear toward HIV/AIDS as a deadly disease with no cure should be replaced with a better understanding and more accurate knowledge about the infection, transmission and prevention in order to help the family to accept more willingly to live together with the PWHAs.

♦ **The PWHAs** who are considered as a final target or beneficiary whose potentials should be developed in running the home and community-based care system since they are more aware of their own vulnerability and have much greater stake in the adequacy and appropriateness of the service provided.

HIV/AIDS Epidemic: National Situation and Responses

Only a few years after the first AIDS case in Thailand was identified in 1984, number of PWHAs have increased at the unprecedented rate. The official statistics on HIV/AIDS epidemic at the national level revealed that since September 1984 to September 2000, there were 170,573 reported AIDS cases (this is not to mention about the estimated million of HIV infected persons). The highest number reported is in the North, followed by the Central, the South and the Northeast respectively. In year 2000, there were approximately 60,000 HIV infected persons and AIDS patients who were recipients in the hospital health care service system. It is estimated that PWHAs occupy no less than 5,000 hospital beds, and the cost of medical care would be no less than 37,000 million Baht. This amount has not yet included the cost of Anti Retroviral Drug (ARV) which majority of AIDS patients have not had an access, and some patients paid for the Drug out of their own pocket.

At present, there is an indication of the declining trend of new HIV infected cases. However, it is expected that in the near future demand in health care services and facilities will greatly increase by the accumulative number of HIV infected persons (since mid 1990s onward), who will gradually become AIDS patients. It would require the government to be much more efficient in allocating budget to serve such needs while greater community support and participation in caring of PWHAs will be more significant.

Although the first AIDS case in Thailand was reported in 1984, the development of National AIDS prevention and control policies and programs was delayed through much of 1987. Thailand has gradually become the AIDS epicenter of Southeast Asia. However, over years the Thai government has impressively responded to combat the epidemic through various channels. In early period, as the epidemic continued to spread rapidly throughout the country, the national measures were narrowed in scope and limited to legal and medical solutions. The proposed legislation "AIDS Bill" called for classical contagious disease control methods such as confinement of infected persons and mandatory testing. The proposal to establish the sanitarium for infected persons rested on CDC principles similar to those used in controlling a communicable disease such as leprosy, quarantining infected persons or excluding them from many 'normal' activities to protect others from infection (Porapakkham et al., 1995). These proposals were however not well received by the public as they violated basic human rights. The use of day care center which was first initiated seemed not to be a good choice. These centers cannot be similarly managed all over the country because of the different socio-economic and cultural context. On the other hand, the initiation of half-way home or hospices to provide shelter and care as well as the occupational training for PWHAs was strongly rejected by the community and the public who were then not yet prepared and unwilling to live with these people. Because of a strong discrimination and social rejections, hospital-based care became major source to provide health care services for the PWHAs. The rapid increasing number of PWHAs in later

years, however has imposed much burden to the government in terms of health personnel, facilities especially hospital beds. At this turning point, the concept of home and community-based care, therefore has been introduced as the alternative in providing continuous care for PWHAs with the support from the government and non-governmental organizations.

HIV/AIDS Epidemic: Regional Situation

In the North, especially **in upper Northern provinces** (Chiang Rai, Chiang Mai, Payao, Lampang, Lamphun and Mae Hong Son), have been severely struck by the HIV/AIDS epidemic since early 1990s. The first AIDS case was reported in Mae Chan District, Chiang Rai in 1988. Since then, HIV/AIDS cases were reported to increase rapidly in Chiang Rai as a leading province and followed by the remaining 5 provinces. The peak of the epidemic was during 1987-1994 when the reported AIDS cases were about half of the national records. Until the present time, the Northern provinces still maintain its highest rank although there has been the evidence indicated declining of new infected cases. Because of the severe HIV/AIDS situation in this particular area, various organizations; government, non-governmental and private charitable organizations, locally and internationally have invested much effort to combat the epidemic and find solutions for AIDS-related problems. The assistance of all forms that came in from these organizations over the decade has helped a great deal in maintaining the continuity of developmental process of home and community-based care in the Northern region.

The HIV/AIDS epidemic in **the Central region** has taken place in a much later period compared to the North. The records from 1994 to 2000 indicated that there has been a continuous increasing of AIDS patients, and the rate tends to be higher than that of the national average. The peak of AIDS cases was recorded in 1999, that is 53:100,000 population (compared to 41:100,000 population at the national level in the same year). However, the total rate of AIDS cases on the regional level has declined to 37.78: 100,000 population in 2000, but the situation in many provinces has not yet much improved especially in Bangkok Metropolitan Area (BMA) where large number of PWHAs has concentrated. The rapid spread of HIV/AIDS in the Central region is facilitated by many factors including large number of tourist attractions and entertaining and sex service establishments, industrial and agricultural industries (fisheries) where large pool of illegal in-migrants are employed. These migrants tend to have risk behavior that leads to a rapid spread of HIV/AIDS.

Based on the national HIV/AIDS statistics, the HIV/AIDS epidemic in **the Southern provinces** tends to increase more rapidly but the rate is still lower than that of the North and the Central regions. The highest number of AIDS cases were reported in Ranong and Phuket provinces which were ranked among the highest 10 provinces of the country. There is also the evidence of larger number of the PWHAs who requested for care and treatment at the hospitals. Among these patients, 80 percent of them need a continuous care and treatment for their chronic symptoms. In addition, it is reported that AIDS cases could be now identified in large number of communities while number of those who died

of AIDS are also increased. Similar to the Central region, a large pool of illegal in-migrants who are hired as unskilled labor, have high risk for infection (sexual behavior and drug use), tourism that pulls a large number of tourists into the areas, drug users, entertaining and sex service establishments along the borders, are contributing factors for a rapid spread of HIV/AIDS in the region.

Statistics from the AIDS Division, Ministry of Public Health revealed that the rate of AIDS cases reported in **the North-eastern region** was much lower than found in other three regions, that is, 11.7:100,000 population compared to 37.7 in the North, 34.7 in the Central, and 20.6 in the South. However, it was observed that the highest rate reported each year was rotated in different locations. For instance, in the early period of the epidemic, the highest rate was reported in Khon Kaen. Then, in 1997 it was reported in Ubon Ratchathani, in 1998 was reported in Nakhon Phanom and the latest statistics in 2001 showed that the highest rate (26.3:100,000 population) was reported in Loei province. This rotation has suggested that in fact the HIV/AIDS epidemic has spread throughout the whole region. However, the vast land area of this region makes it difficult for its population to fully realize the threat of the HIV/AIDS epidemic. In addition, because of the discrimination against PWHAs has been quite strong, the PWHAs, therefore were compelled not to reveal themselves until they have become very sick and seek for treatment. This situation imposes difficulty in providing health care service to these patients. In many ways, the concealment of PWHAs has greatly affected the accuracy of regional HIV/AIDS statistics.

The major factor accelerating the spread of the HIV in this region is large volume of population movement and highly mobile including seasonal migration, circulation, in- and out-migration that caused by economic hardship, and poverty existed in this region.

Home and Community-Based Care System: Regional Strategies Development

The growing of HIV/AIDS at the unprecedented rate in the Northern region, especially in **the upper Northern provinces** (6 provinces) has gradually forced the whole community to adjust themselves in order to live with the problems in the more harmonized manner. Over years, various home and community-based care strategies in the Northern region have been initiated, developed and implemented. The development of home and community-based care strategies in this region has evolved in 4 subsequent periods.

The first period "Self care" (1988-1993).

This "depressive period" was the most difficult time for PWHAs who were rejected by their own family, community and general public. Irrational fear and discrimination against PWHAs was so strong due to the lack of understanding about the infection in terms of transmission, prevention and treatment. Self-care was the only approach which most of PWHAs depended upon while searching for alternative care and treatment and lending help to each other.

The second period "Care through Self-Help Group" (1994-1995).

Conflict between a self-claimed doctor (a so-called angelic healer) who offered the herbal medical tonic claiming to cure HIV/AIDS, and the Chiang Mai Provincial Health authority who worried about the detrimental effects of the herbal treatment on the health of HIV carriers, had brought about the evolution of HIV/AIDS self-help group through a strong support of NAPAC, one of the NGOs, negotiated with the government for freedom to choose the alternative treatment. This period was known as a "unionized period" since the number of HIV/AIDS self-help groups increased more than double from 13 in 1994 to 35 groups in 1995. At the end of 1994, the Government advocated and committed to provide full support for the PWHAs groups through the special organization; Northern AIDS Coalition Center (NACC) set up to support, coordinate and promote the participation of communities in handling the AIDS-related problems. These self-help groups were also encouraged to work together as a network. In 1995, as a result of the Third International Conference on AIDS in Asia and the Pacific held in Chiang Mai, the first HIV/AIDS networking was set up to protect their benefits and their rights from being discriminated in all forms.

The third period "Care through HIV/AIDS network" (1995-1998).

During this period (known as "dispersed period"), the number of 'self-help groups' had increased dramatically from 79 groups in 1995 to 105 groups in 1997, and to 195 groups in 1998.

The major reason for such a rapid growth was the government budget allocated to support activities of the PWHAs' self-help groups. In addition, many PWHAs decided to return to live openly in their own community since by this time they were more accepted. However, problems of PWHAs have extended from health care issue to other extent such as economic (financial constraint), occupations and living conditions. Under these conditions, the elderly and young children in the family were most affected. During this same period, the PWHAs network received greater financial support from the government through the Ministry of Public Health to be able to develop itself into a more structured system through the administration of the committee at various levels. The PWHAs self-help groups had become more active and involved in various activities apart from a regular home visit program. The PWHAs groups were more accepted to participate in the community activities, gained more recognition and received greater support from community members.

The fourth period "Care through the HIV/AIDS network and the community" (1999-present).

In 1999, number of PWHAs self-help groups in the upper North had grown to 209 groups and increased to 278 groups in June 2001. The mandates of the PWHAs network, however extended itself to involve more in social commitment with other networks and organizations. This period is known as a "reconcile period" since the network has encouraged the PWHAs and the community to live together in harmony. This attempt has helped

a great deal for the community-based care for PWHAs becomes more accepted by the community members, and strengthened the community's potentials to learn and be able to solve their own problems.

The brief description on the evolution of home and community-based care strategies in the upper Northern provinces has suggested the importance of involvement and continued support of various organizations in laying out the firm foundation of the system. These supports have gradually empowered individual PWHA to move out from 'self care' stage to be taken care of by the group, by the network and by the community.

The home and community-based care approaches and activities carried out by these self-help groups are varied according to the group's background, objectives, administrative purposes and financial condition. The approaches include health care service (home visit, alternative treatment, self-care, traditional medicine), exchange of updated information and accurate knowledge, economic assistance, occupational training, promoting community participation in providing care, encouraging the PWHAs and the community to live together, campaigning for AIDS prevention, protection of PWHAs' rights.

The spread of HIV/AIDS epidemic in the three remaining regions has been clearly observed in much later years, but when the number of PWHAs have already broken out at the alarming rates while the public has not yet well-prepared to live with this fact. Unlike the Northern region, this 'outbreak' of HIV/AIDS epidemic did not allow these three regions to have sufficient time to prepare the community to gradually learn and adjust them-

selves to live with and care for PWHAs. Therefore, the home and community-based care strategies used in these three regions have been mostly transferred, or learned from past experiences of the North, or through exchanging of information among each other, then adopted without much consideration regarding their socio-economic and cultural context. These approaches, therefore are not much different from each other and the initiatives of various organizations to render assistance to PWHAs are rather similar. The family is still the basic social component where most of the burden in providing care and emotional support fall upon its shoulder. In some areas where the family cannot bear the burden or denies taking role of caretaker, there usually be other community-based organizations to take such responsibilities through different activities. In three regions, the most obvious community-based organization that has played a significant role in providing care and alternative treatment is religious institution especially the Buddhist temples and monks. Many temples and charitable foundations, especially in the Central region have turned themselves into hospices, providing shelters to PWHAs who are rejected by their families and communities. Some monasteries care for the sick persons until their terminal stage. Buddhist monks have taught meditation, offer various types of alternative treatment including herbal medication. Indigenous healers have become 'new hope' for many patients who are unable to afford high cost of ARV. The government role in providing care services (mostly through hospitals and health centers) in these three regions is quite sufficient but rather passive due to many limitations such as lack of manpower for hospital-based care,

while medical care facilities could only be provided at certain extent. Home visit activity by a medical team cannot be carried out openly because of social stigma that could greatly affect PWHAs and families. However, the hospitals and health centers still be the last resorts where the AIDS patients' needs for treatment of the opportunistic symptoms are usually served and be taken care of. ***In the Central region*** where the level of discrimination against PWHAs has been high and degree of community participation is rather low, non-governmental organizations have played significant role as supplementing agencies providing additional support and fill up gaps whenever the assistance from the government organizations are lacking. ***In the South*** where the role of non-governmental organizations is less obvious compared to those in the Central region, groups of volunteer leaders have played a leading role in providing assistance to PWHAs and their families (holding various workshops, occupational training and strengthening the PWHAs' ability to help themselves). With regard to care, the following services are given; counseling, health education, economic assistance, home visit. All these activities aiming at improving PWHAs' quality of life. ***In the Northeastern*** region, care is mostly provided in the family, or by the religious institution, or by the self-help groups with the support of hospitals while the community has minimal role. The non-governmental organizations and foundations were set up in many provinces but many of them work on an ad-hoc basis. Many of them died out after their task was over due to the limited budget.

Key Mechanisms to Sustain Home and Community-Based Care System

As mentioned earlier, the three regions (Central, South and Northeast) have faced AIDS-related problems in much later period compared to the North. Many of the home and community-based care approaches implemented in the North become 'lessons learned' that have been adopted totally or slightly adjusted by other three regions as strategies in providing health care services to the PWHAs. However, by adopting the strategies proved to be successful in one location does not always guarantee the same result in other locations. The success in implementing these strategies, in fact is determined by 4 significant mechanisms that operate home and community-based care system. These four mechanisms include the PWHAs, family and community, non-governmental organizations, and the governmental organizations or the State.

The PWHAs: The first mechanism.

Although the PWHAs are considered to be the beneficiary of this care system, they are also very important basic mechanism that could facilitate or obstruct the development of the system. The PWHAs' health conditions, including physical, mental and spiritual, as well as their potentiality are basically important qualifications that allow them to initiate and carry out activities or programs that beneficial to their own well-being. In the Northern region, especially ***in the upper northern provinces***, the pressure from being discriminated against by the public has

forced PWHAs to form up self-help groups to help and support each other. Later, these groups developed themselves into a well-structured network where their basic rights could be protected, and be able to negotiate for their well-being. With this strength and greater understanding of the public about the disease and prevention, the PWHAs in general are more accepted and be able to lead their life more normally in their own family and community. However, through times only groups with strong leadership and fully committed members can be survived and sustained while many of them become weaken and died out. On the other hand, the PWHAs in ***the Central and in the South*** are unable to reveal themselves as much to the public since the discrimination and negative attitudes toward PWHAs have been still very strong among community members. Many of the PWHAs in the South are illegal migrants who concealed themselves, did not have access to health care. Many of them are fishermen whose occupation makes them highly mobile, had little education, and have lived in a poor condition with little access to proper health care. ***In the Northeastern region*** where the area is vast, the mobility of population (in- and out-migration) is high. All these mentioned conditions existed in these regions, without sufficient assistance from other mechanisms have weakened the ability of individual PWHAs in forming up into groups or network to help themselves. Worst, the unwillingness of PWHAs to reveal themselves because of social stigma have prevented them to reach out for proper health care and treatment, and not to be able to exchange useful information to improve their quality of life. With regard to needs and expectations of PWHAs, it is evident that apart from

adequate health care service, both asymptomatic and symptomatic HIV infected persons mostly need assistance socially and economically (financial, occupation) for themselves, and education for their children since they are hardly able to earn a living. These needs and expectation still are rarely served.

The family and community: The second mechanism

In the home and community-based care system, ***the family*** is considered to be the most important basic mechanism in shouldering all responsibilities as caretakers of PWHAs. It is more true in the community where the degree of discrimination against PWHAs is still very strong and the PWHAs are unable to reveal themselves. However, the family has faced a number of problems that have weaken the ability to be a 'better' caretaker. These problems need to be paid much attention to.

a. Most families lack of basic knowledge and understanding about HIV/AIDS, transmission, prevention and basic treatment while they are 'forced' to be responsible for caring of PWHAs,

b. The family lacks of necessary resources for caring including ability to buy high cost medication, basic equipment for caring (antiseptic agents and gloves for daily care and cleaning), no sufficient referral system when it is needed,

c. The family does not have good access to accurate and updated information on treatment, lack of good source of counseling especially at time when the family and PWHAs need an emotional and spiritual support

d. The family lacks of sufficient guidance or advice for

alternative medical care and treatment (meditation, herbal medicine, dietary, supplement food etc). Many PWHAs and families have been taken advantage of by quacks, self-claimed healers by being charged rediculously high price for the treatment with some unidentified herbal tonic claimed to cure AIDS.

The community is another important mechanism in the home and community-based care system. Community include community-based organizations (women group, volunteers), religious institution (monks, monasteries, churches), HIV self-help groups, and community members. It has been said that "The caring community is the key to solve AIDS problem". Therefore, the main question with regard to this issue is that how to promote or encourage the community to involve or to participate more in providing care to the PWHAs.

During the early period of HIV/AIDS epidemic, because of lack of understanding and accurate information about HIV/AIDS, communities in the upper northern provinces rejected to live together with the PHWAs because of prejudice and social stigma attached to the disease. Care for the infected and sick persons was the family matter, not the community's responsibility. During the period of strong government support and convincing documentation of the explosive spread of virus, the number of organizations involved in AIDS control both government and non-government had worked closely giving assistance to alleviate burden of caring, with the additional support from the academic institution over a long period of time. The continuous assistance received from the organizations outside the community had gradually empowered PWHAs to move themselves out from being the

burden of the family, to be able to help each other through self-help group and a well-structure network, learn how to negotiate for the benefits they deserve, and be able to protect their rights to certain extent. Along with this development, community started to recognize the potentials of PWHAs in many ways. On the other hand, the improved knowledge and better understandings about HIV/AIDS have gradually lessen the degree of discrimination against PWHAs while acceptance to live together in the same community has also increased. Since the beginning of the epidemic, religious institution especially Buddhist monks and temples, Church have played significant role in providing care and spiritual support in their own way. Traditional or indigenous healers are another source to provide alternative care and treatment when PWHAs need. In fact, most significant role of these healers lie in the social dimension rather than the medical aspect.

In the ***Central region,*** it is obvious that the participation of the community in providing care has developed at a much slower pace although the epidemic is already widespread almost throughout the region. This 'alienation' phenomena is attributable by many factors. The understanding of the public and accurate information about HIV/AIDS are lacking while number of PWHAs increased dramatically, health education with regard to prevention seemed to be inadequate in preparing the public have led the community in general deny to 'share space' with. The negative attitudes toward PWHAs have reflected in various forms of discrimination. At the same time, in many areas the policies on budget allocation, the management and administra-

tion with regard to the HIV/AIDS control, prevention and care provision have inconsistently operated among organizations involved. More importantly, the value of 'individualistic' has strongly imbeded among population in communities in Central region. Former 'traditional and agricultural' communities have developed and transformed themselves to be more urbanized, more industrialized, and more city-like communities. These changes make the communities become more alienated, and not depend on each other as much as before. In addition, the community structure, in terms of relationship among members has become looser. The definition of 'a true community' becomes unclear. In the Central region, therefore, the temples and hospice managed by Buddhist monks and religious foundations have become a significant unit to provide 'community-based care' for PWHAs who are rejected by their own family or community. However, because of the lack of management skill, some temples which provide shelters for PWHAs, have developed some conflict with the community members who did not agree to have such services in the community.

In the South, although level of discrimination against PHWAs could still be observed but level of community participation through various channels is much better than that of the Central region. One of strategies used to promote the community participation is through leadership of community leaders and volunteers of various groups. Buddhist monks actively provide traditional medication and alternative treatment as well as shelters for those PWHAs who need it. On the other hand, the Islamic religious leaders and the community members have also played

significant role in providing care for their members who are infected or sick. The provision of care is based on their strong and faithful beliefs to help the sick and the needy. Moslem women have changed their traditional roles as housekeeping to be more actively involved in caring of PWHAs through home visit and providing assistance to PWHAs and families. On the contrary, in the fishing community, the members are not strongly related to each other because of the nature of the occupation. This has weaken the community ability in terms of caring management. The assistance is limited only in a small circle of close friends or family members. The PWHAs have little access to proper health care and modern medication because of their frequent movement, little education, poor and little contact with other communities. Some are illegal migrants who could not reveal themselves for any treatment. Majority of PHWAs is mostly count on traditional medicine and healers. Unlike situation in the North, the network of traditional or indigenous healers does not exist in this region despite the great demand of PWHAs.

In ***the Northeastern region,*** unlike in the North, the lower rate of HIV/AIDS (compared to other regions) has failed to convince the public to aware of impacts of the epidemic while the negative attitudes toward HIV/AIDS has been still strong because of the lack of understanding. The PWHAs usually do not reveal themselves until they are very sick and need some treatment at the hospitals. In addition, level of population mobility (in-and out-migration) is high. Most of people still understand that the epidemic can be handled by the government or other organizations from outside. The community is not yet ready to

participate or take such responsibilities. The religious organizations in this region have played part in providing care to PWHAs but not as much obvious as found in other regions.

The non-governmental organizations: The third mechanism.

It could be said that home and community-based care system that has been well-developed in the upper northern provinces is partly received a strong and continued support from various non-governmental organizations since the early period of the epidemic in late1980s. Many of these NGOs have strongly committed themselves to solve AIDS-related problems in the area including empowering the family and community to handle the problems, strengthen the PWHAs' potentiality to work as a group and build up the network protecting their own rights. In addition, the academic institutions located in the area have also played their part in providing up-dated information and knowledge necessary for the improvement of the caring system, organizing training workshop, arranging study tour and carrying out research to build up new knowledge to support activities of PWHAs group and network.

However, based on the information available from the three remaining regions (Central, South and Northeast), it is evident that generally the non-governmental organizations have played more active role in preventive activities (campaigning, health education, preventive measures) but was minimized in contributing to the development of the home and community-based care system to operate efficiently compared to the North-

ern provinces. Many of these NGOs work individually on their own rather than cooperate with the Gos. ***In the South,*** only few NGOs have been mentioned to be working in the area and their role in supporting the community-based care has been at minimal. On the other hand, ***in the Central region,*** large number of non-governmental organizations (especially in Bangkok area) have worked more aggressively, compared to the governmental organizations. However, the program evaluation indicated that many of these NGOs have faced problems of their own in terms of administration, management, qualified manpower, resources, and financial support that affect their ability to continue working in the long term. ***In the Northeast region,*** this mechanism is also found not to function well as that in the Central region. In addition, many of NGOs do not have clear objectives in carrying out their activities since they are set up on a more ad-hoc basis. These NGOs work as long as the budget allocated to them lasts, then died out. These limitations of NGOs directly affect the development or sustainability of the care system.

The Governmental Organizations or the State: The fourth mechanism.

The home and community-based care program has been first initiated by the government to encourage family and community to share responsibilities in providing care and emotional support for PWHAs which are expected to be better than other organizations. Since the beginning, the Thai government has impressively responded to the AIDS epidemic including the declaration of National AIDS policy began in 1987, set up

National AIDS Control and Prevention Committee, establishment of the AIDS coordinating agencies at various levels (from national to sub-district), increased AIDS budget exponentially, provide continued support for medical care and treatment, and socio-economic support of PWHAs and their families. The serious situation of HIV/AIDS epidemic in the upper northern provinces urged the government to invest much effort and resources (budget, manpower) as well as to establish special organization (NACC) to support activities of PWHAs and community. The long-time and continued support from the government has helped the home and community-based care system in this region to be well-developed and more established. However, the observation made in other three regions indicated that role of government in supporting the operation of home and community-based care has not that strong and less efficient than it was done in the North. This may due to the fact that the HIV/AIDS epidemic situation in these three regions seemed not to be serious as it appeared in the North. Most of the support from the government therefore has been operated through regular bureaucracy channels (provincial, district and sub-district organizations). In addition, the high degree of rejection and discrimination against PWHAs existed in these regions has prevented the government health team to play role more actively in providing health care service to those who need it. Moreover, it is found that the cooperation between government and non-governmental organizations are at minimal level that makes the system operate less efficient than it should be.

Conclusion: Lessons Learned and Future Prospects

In sum, based on the comparison of the existing home and community-based care systems operated in the four regions, it could be said that approaches and strategies initiated to provide care and treatment of PWHAs in these four regions are similar to each other. These strategies have been mostly transferred, learned and shared among each other, then adopted without much consideration on their local situations. However, when the comparison of mechanisms that are vital to the succcss of the operation of the caring system is made, much differences could be observed. These differences have attributable by the regional different socio-economic and cultural context.

In the North, as repeatedly mentioned, the well-structured home and community-based care has been gradually developed over long period of time. The PWHAs were pressured by rejection, discrimination from their own community, to seek for assistance for survival. Being dependent upon the assistance from the government and hospital-based care seemed to be inadequate. The PWHAs formed up the self-help group and developed themselves to be working as a network in providing care and other assistance to their members. The network has been able to pull in resources from various sources including government, non-government, private organizations,and academic institutions for the development of community-based care system. With this strength, the network gradually received support from their own community, and PWHAs have been accepted to lead a

normal life among other community members. This developmental process has shown that the strong mechanism at the community level and 'people power' have been able to work on a more equal term as 'partners' with the government organizations. The system has become the alternative in providing care for the infected and the sick persons in their home and community. At the same time, the community members have gradually learned to be more independent in dealing and solving the problems of their own. However, it does not mean the well-developed system and implementation of the program in this region has undergone without any problems. Many of the PWHAs, at present still do not want to reveal themselves which makes it difficult for health care providers in reaching out this group. On the other hand, the management and administration of the self-help groups and the network need to be improved in various aspects including the strengthening of potentiality of members of PWHAs groups and network to be more independent. The NGOs which play important part in the development of home and community-based care, may also have to redefine their roles and extend their commitment to cover wider aspects other than the HIV/AIDS issue. Greater coordination among tri-parties; government, non-government and community is also needed. The role of government or non-government organizations in helping the community should also change from being a "baby-sitter" to a "more equal partner" so that the PWHAs and the community could be less dependent and be able to help themselves better.

The existing mechanisms in other three regions seemed not to operate efficiently in pushing forward the home and

community-based care system to a more successful level. The epidemic in the three regions broke out in the midst of negative attitudes, irrational fear of a disease, and strong discrimination against PWHAs. Community members did not have common belief in the need to help since PWHAs were still taken to be sexual perverts, promiscuous and drug addicts. Worst, public was not 'ready' to accept the idea that PWHAs could live in the same community with them. The home and community-based care programs in these regions, therefore are implemented under the 'not ready' and not well-prepared conditions, especially at the family and community levels. For PWHAs who are rejected by their families or those who cannot live in their own community, the temples, hospices where the shelters are provided become their last resort to live, and to die. Again, while many of the religious institutions have operated under the religious principle "helping the needy to gain greater merit" most of them lack of sufficient support in terms of financial, manpower, and mana gement skills. Some services are found to be sub-standard that could have the detrimental effects on quality of life of PWHAs. The NGOs which was a strong mechanism in the North seemed not to operate with the same strength in three regions. In ***the Central regions,*** a large pool of NGOs have worked quite aggressively in helping the community-based care system move ahead and be able to fill up gaps where the governmental organizations cannot fulfill. However, many NGOs have their own problems in various dimensions that deterred their work to be more sustained in the area. On the contrary, ***in the South*** role of NGOs has been minimal while other community-based organi-

zations, volunteer groups and religious institutions played more significant roles. ***In the Northeast,*** the 'less serious' epidemic situation, high population mobility in the vast area, lack of awareness about the situation, high degree of discrimination, all together have weaken the efficient implementation of the home and community-based care program. The family and the community are not well-prepared to shoulder the burden of caring. The NGOs have not sufficiently worked in the area and many of them are set up in a more ad-hoc nature. The religious institution is not yet sufficiently supported or well-developed to be responsible for this burden.

Finally, the role of government organization in providing support for the development of the home and community-based care in these three regions seemed to be much less aggressive than what already occurred in the North. Many activities are operated in a more routine and passive manner due to many reasons as earlier mentioned. Most important, the government organizations rarely act as a 'messenger' who transfers knowledge and past experiences both right and wrong, success and failure that occurred in the North for other three regions to learn not to repeat the same mistakes.

Issues that Need to be Reconsidered

Home and community-based care system has been initiated and expected to be the alternative strategies in providing better care for PWHAs at present time, and in the future when a large pool of HIV infected persons become sick. In order to imple-

ment the strategies in a more effective way for future use, there are few issues that need to be reconsidered, and taken into consideration.

First issue: At present, quite a large number of HIV infected persons still do not want to reveal themselves because of great negative impacts they may get from the public. The question is that how the community, PWHAs self-help group, or network could extend their assistance directly or indirectly to these people. Or, how these people, without revealing themselves could have access to proper health care services in a more equal term to those who open up themselves and be able to develop their potentials to lead more normal life in their own community.

Second issue. In this new dimension of care, the family and community are considered to be the most important social mechanisms in providing care to PWHAs since they have a closed bond with the person. Therefore, how to prepare and equip these two social units to be able to take such a heavy burden which earlier was the hospital's. Some indicators have been invented to measure the potentiality of the family and the community in providing care for PWHAs. The indicators include: more PWHAs revealed themselves, more families and communities accept to live together with PWHAs, more families provide care at home for PWHAs, less PWHAs seek for other shelters than their home, more PWHAs have greater access to health care services, and less PWHAs are rejected.

It is fully realized that the AIDS epidemic is in fact a long-term problem. To enable the community members to help themselves in the long run and to sustain the community-based

care program, it is essential to teach the community to be independent from the assistance of outsiders as much as possible. This concept will be of special value in the future when the resources from the GOs and NGOs are no longer available or become inadequate to cover cost of caring for the rapidly increasing number of families with PWHAs. To reach these ends, the family and community should be strengthened or empowered through various approaches such as providing the opportunity for the community to learn and be confident in their own wisdom; reorganizing the relationship structure within the family and community in order to encourage the members to think and to work as group or network as to empower themselves, and participate in problem-solving process; provide the opportunity for the community to learn how to manage or administer the new caring system most effectively within the limits of available local resources.

Third issue. The religious institution plays significant role In providing care to PWHAs in the community since they could be depended upon spiritually and mentally by the PWHAs and their families. Many Buddhist temples have turned themselves as the last resort to care for the sick and the dying persons who are rejected by the community. Many monks have taken the role of 'traditional healers' who provide the herbal medication and other alternative care and treatment. Under this new development, it is important to review the following issues such as how much and how far the religious institutions play this role and not to overshadow their true role as spiritual leaders? Should the temples turn themselves into hospice or hospital-like facilities

to care for the sick and the dying while their basic function is only for religious-related activities? If conflicts arise in setting up the hospice in the community in the midst of community rejection and discrimination, how well the temples handle the situation? Or should the temples only play supplementing role in supporting the family and community to care for their members? Or, if the religious institution should also take part in the caring system, who will be responsible to develop their potentiality to a full scale with an acceptable health care standard?

Fourth issue: The development of knowledge body with regard to home and community-based care is lacking although the system has been implemented in various locations for about a decade. This lack is due to many reasons;

a. The organizations, either government or non-governmental who work in the area did not systematically compile information or keep records in written form where the reference could be made. Many of them worked without taking field notes. Most of the information exchanged and lessons learned among each other mostly are obtained through 'verbal' instruction, observations, study tour which are only 'cross-sectional' learning process, while holistic picture cannot be assessed. The transfer of knowledge and experiences to be implemented in other areas, therefore tend to be incomplete, that usually lead to the unsuccessful operation. .

b. Most of research work carried out in the past years focussed their attention to 'forms and measures or approaches' used in home and community-based care system rather than analyzing the system holistically. This is due to the limited research

budget, manpower, and time frame in carrying out field study. Therefore, the results obtained from each study project become 'piecemeal' which are not much of use for the development and improvement of the system.

c. One aspect of home and community-based care which is largely negligent by most of researchers is 'care of dying'. Providing care for PWHAs should not limit itself to only physical health care but should also extend to the 'spiritual care' or 'mental support' through arranging symbolic ceremonies which is meaningful for everyone involved, especially at the terminal stage of the dying persons and their families. This kind of spiritual support can only be best performed by the family and the community which are close to the heart of the PWHAs.

It is trusted that if the 'past experiences' are well-recorded and 'passed on' more systematically and properly, these experiences could be very useful lessons for all the parties involved to learn both success and failures. The successful 'model or strategies' in one area does not necessary mean to be successful in other areas since each area has been determined by different epidemic situation, different socio-economic and cultural context. And most important, the mechanisms existed in each area also operate differently. The models or strategies, therefore have to be studied carefully and adapted accordingly to reach the final end, that is the PWHAs' better quality of life.

References*

AIDS Division, Ministry of Public Health; WHO; and Institute for Population and Social Studies, Mahidol University. (1999). **Study on the Community Based Care for HIV/ AIDS in Thailand.** A paper presented at the Conference on Community Based Care for People Living with HIV/ AIDS: Lessons Learned from Thailand and Future Perspectives. April 19-20, 1999, Ambassador Hotel, Bangkok.

Porapakkham, Y; Pramarnpol, S; and Athibhoddhi, S. (1995). **AIDS Policy: The Case of Thailand 1984-1994.** Bangkok: P.A. Living Ltd.

Moodie, R; and Aboagye-Kwartang, T. (1993). "Conflicting the HIV epidemic in Asia and the Pacific: developing successful strategies to minimize the spread of HIV infection". **AIDS** 7: 1543-1551.

Rau, B. (1994) "AIDS and communities: lessons for policy makers". **AIDSCAPTIONS** (FHI Vol.1 No.2 May: 31-32).

Coghan, A; Kabandu, M; and Musungu, MJ. (1994). "Empowering communities to fight AIDS through participatory evaluation" **AIDSCAPTIONS** (FHI Vol.1 No.2 May: 16-18).

* These references are additional documents to those already provided in the Thai report.