

Development of Home and Community Care for AIDS Patients in the Socio-cultural Context of the Central Region, Thailand

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Abstract

This study reviews experiences of home and community-based care for AIDS patients and presents strategic suggestions to support home and community care (HCC) in the socio-cultural context of the central region of Thailand. It reviews a variety of documents and lessons learned on HCC for AIDS in this region.

The results of the study reported the same problems that many AIDS patients are confronting with community's negative attitude towards people living with HIV/AIDS (PLHIV). The key finding of the study is that most AIDS patients are cared for at home. Buddhist temples, Christian charity homes and NGO temporary shelters are alternatives for those whose families are poor or who have been abandoned by their families. For PLHIV, self-help groups organized by public hospitals or NGO staff are helpful and needed. Home visits performed by these staff are also appreciated. Strategies suggested for HCC development are: 1) Restoring the traditional Thai caring culture. 2) Empowering community organizations to support PLHIV to get access to better care. 3) Strengthening the collaboration among HCC stakeholders to improve the efficiency of the whole health care system. 4) Establishing active participatory communication networks among stakeholders through a variety of innovative and interactive communication channels and media. All stakeholders should be enabled to speak out and share health information and support according to the health needs of the PLHIV and other community members.

Keywords: home and community care, AIDS, socio-cultural context.

Introduction

From September 1984 to 2007, official statistics reported about 1.1 million cases of HIV infected persons in Thailand. The highest numbers were found in the North, followed by the Central, the South and the Northeast region respectively. In the year 2000, there were approximately 60,000 HIV infected persons and AIDS patients who were recipients of care in hospitals over the country (AIDS Division, Ministry of Public Health, 2001-2007). It was estimated that they occupied no less than 5,000 hospital beds, with the cost of medical care estimated at no less than 37,000 million Baht. Yet, a much greater amount was spent on Antiretroviral Drugs (ARVs) provided by the Thai National Universal Coverage for Health Care and Thai Social Security scheme.

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Records from 1994 to 2000 indicated that there had been a continuous increase of persons living with HIV (PLHIV) in the Central region, and the prevalence rate tended to be higher than that of the national average. The peak of HIV prevalence was in 1999 at 53 per 100,000 population. While the rate of HIV on the regional level decreased to 37.78 per 100,000 population in 2000, the situation in many provinces did not improve much especially in Bangkok (Bureau of Epidemiology, Department of Disease Control, Ministry of Public Health, 2000). The rapid spread of HIV/AIDS in the central region is facilitated by many factors, such as a large number of tourist attractions, entertainment venues and sex services. In the industrial and agricultural sectors, a large pool of unregistered cross-border migrants were employed and were thought to have risk behaviors that could lead to the spread of HIV (Bureau of Epidemiology, Department of Disease Control, Ministry of Public Health, 2000).

At present, there is an increasing trend of new HIV cases. It is estimated that these new cases are about 12,787 persons per year, and most are adolescents aged 15-19 years old (Institute for Population and Social Research, 2009). Therefore, it is expected that in the near future the demand for health care services and facilities will be greatly increased by the cumulative number of PLHIV (from the mid 1990s onward), who may gradually become AIDS patients. Consequently, the situation requires the Thai government to be much more efficient in allocating budget to serve these needs, while greater community support and participation in care become urgent needs. This critical situation has driven the Thai government to revise the existing health care service system to enhance the capacity to provide adequate services, as well as to search for alternatives that could efficiently serve needs and improve PLHIV's quality of life. Among many approaches, home and community-based care (HCC) has been initiated as the most suitable strategy to deal with these needs (Oulid, 2000). This strategy is meant to maximize utilization of the existing and available resources within the community since family and community's participation are basic components of care provision. However, it is recognized that in operating home and community-based care, coordination and continuous support from multiple sectors such as governmental, non-governmental, charity organizations, religious institutions and community-based organizations should also be activated (AIDS Division, Ministry of Public Health, WHO and Institute for Population and Social Research, 1999).

Family and community participation is the most frequently addressed strategy on HCC for PLHIV during the past decade, partly because AIDS patients live in communities where discrimination and stigmatization are often a factor. However, families and communities have not yet been well prepared to shoulder the new responsibility in caring for AIDS patients. In many communities, the negative attitude toward and discrimination against PLHIV is still very strong, especially in the central region. Therefore, many PLHIV have established their own self-help groups or network to care for each other and protect their rights.

Studies on HCC for PLHIV in the central region are rather few. Inadequate knowledge of family or home-based care together with the individualistic, liberal-urbanized capitalistic socio-cultural context of the central region may contribute to constraints rather than benefits for home and community care policy and practice.

The present study attempts to find these issues through analyses and synthesis of knowledge and experiences of HCC for PLHIV in the socio-cultural context of the central region, including a field study in five areas. The results of the study hopefully will lead to the improvement of the Home and Community-based Care (HCC) system for PLHIV in the future.

Objectives

1. To analyze and synthesize the knowledge and experience of HCC for PLHIV in the socio-cultural context of the central region.
2. To present strategic policy suggestions for supporting home and community care.

Methods

1. Review and synthesize a variety of documents and lessons on HCC for PLHIV in the central region of Thailand, including research studies, postgraduate theses, NGO annual reports, and project reports conducted both by GOs and NGOs. More than 70 studies carried out from 1993 to the present were reviewed.
2. Conduct a field study in five areas of the central region, namely Bangkok, Ang-Tong, Sing Buri, Pathum Thani and Nakhon Pathom. Methods used were participatory observation in the community, in-depth interviews at the hospitals and then group discussions or home visits.
3. Discussions with NGO delegates about the situation of home and community care.

Background

Home and Community-based Care (HCC): basic concept and definition

According to the World Health Organization (WHO), home care or home-based care refers to the provision of care for patients who are in a household setting where family members are responsible for caring tasks (Bos & Leutscher, 1995). Additionally, in care for AIDS patients in Zimbabwe, Dube (1993) suggested to extend the meaning of home-based care to cover care provided by hospital staff or health professionals in the form of extended hospital care through home visits, including psychological or spiritual supports to PLHIV at home.

In this study, researchers define home-based care as all kinds of care including bio-psycho-social and spiritual aspects provided for PLHIV, by family members, community health volunteers, or health professionals at home setting. By this definition, the boundaries and dimensions of care are expanded to respond to the recent HIV/AIDS situation.

Community-based care is more complicated since “community” refers not only a physical setting of a locality, or a group of people living in the same area, but also refer to relationship among members who live within or outside the same physical compound, and share common objectives and activities to solve problems that are challenging to members’ wellbeing. (Kuawhavong, 2000).

The initiation of home and community-based care system is owing to the progress of epidemic situation and increasing needs of care for PLHIV in all regions of Thailand. However, the regional socio-cultural context is proved to be one of the significant determinants of the success or failure of home and community-based care.

Socio-cultural context of the central region of Thailand

The central region of Thailand has been the origin of development in all aspects since the thirteen-century: from the Ancient Kingdom of Sukhothai, Ayudhaya and Rattana-khosin (Chiengkul, 1983). As the centre of the state and political power, the regional population experienced both acceptance of and conflicts with new ideas, practices, rules and systems that dynamically changed over time. The socio-economic and cultural transitional process was affected by a variety of internal and external factors from inside the country and invasive movements from western countries, especially during the age of colonialism. The cultural trait of enthusiasm towards new things among young Thai elites has led to a range of contributions to ease the social transition in many aspects, including economics, education, health, politics, etc.

Since 1855, through the Bowring Treaty with Britain, the central region has been the first region exposed to westernization and modernization. Changing from a self-sufficient, agricultural production and barter system to a commercial economy resulted in a shift in people's way of life and thinking. This change occurred, firstly among the elite then to the majority, who later became the middle class and labor class of the society.

During 1960-1980, there were other great changes in economic aspects of the central region. Agricultural-industrial technologies were imported resulting in the stimulation of rice production to export to the world market. The results brought an end to some traditional ways of life as well as beliefs, rituals, and social interaction among people. The concepts and characteristics of urbanization and capitalism became the mainstream culture of the people, especially of those inhabitants in Bangkok and provinces nearby (Chiengkul, 1983). Dramatically, modern urbanite characteristics were formed replacing traditional ones. The cultural traits of modern urbanites such as individualism, independence, self-reliance, privacy, small circles of social interaction, sensitivity, fluidity and dynamism emerged in the central region, from cities to rural communities, especially among the young generation (Natsupa, 2010; Hannerz, 1980). Consequently, Central Thai residents may, have a weaker sense of community unity as compared to other regions of Thailand.

These characteristics contribute to the challenge of addressing the HIV/AIDS epidemic in the region. The answer to the question of whether this mainstream socio-cultural context supports or obstructs the policy and strategy of home and community based care is still not clear. The question is a challenge for future research as well as for public health policy making.

Results

Documentary review

A total of 67 papers were reviewed during the study. The process of selecting high-quality research that fit with the objectives of the study resulted in a total of 15 research reports and 9 master theses to be used as the main source of data. These research studies were launched during 1991-2001, with areas of study covered knowledge and attitudes towards AIDS of PLHIV and their families, care for patients at home, and forms of community-based care in Bangkok and other central region provinces. Studies conducted during 1993 and 1994 revealed that most families and communities still had strong prejudice towards PLHIV, though health information about HIV/AIDS was easily accessible to the public by that time. Fortunately, the situation has improved since 1996. Later studies reported improving attitudes and acceptance of PLHIV and home care, though they did not critically analyze the process that led to the improvement. The pressure of the size and severity of HIV/AIDS crisis, together with increasing experience in care may have contributed to the better situation.

Vasigasins' (1996) study on community acceptance behaviors and attitudes towards PLHIV showed that social status, media influence and relationships with PLHIV were factors related to the acceptance as community members of PLHIV and their families. Additionally, the study suggested that health information should be presented to the public regularly and continuously for improved understanding. A number of studies pointed out that knowledge and understanding about HIV/AIDS and care among PLHIV and their home caretakers was not adequate and inappropriate. However, the optimal solutions were not suggested in these studies, and the participation of PLHIV and their lessons learned were not reflected, especially in light of the central region's socio-cultural context. At the same time, the content of health education materials and counseling was found to be impractical for use by lay people, with practical health information inadequate both in quantity and quality. "Voices" and "needs" of PLHIV were not communicated to the public.

Consequently, PLHIVs real needs were not effectively fulfilled through services provided by governmental and non-governmental sectors. PLHIV still had to struggle with stigma and discrimination from the community, and few dared to disclose their health problems. These studies outlined the three models of care provided to PLHIV: formal health care (curative and supportive care) in the public hospitals and community health centers; psycho-social care in NGOs programs; and activities provided by government health care workers and/or NGOs staff in the form of "self-help groups" or "social support programs", such as providing complementary or part-time jobs, home visits, and health counseling.

From 1988 to 1996, research about community actions in HIV/AIDS prevention and problem-solving were rather few (Sornralum, 1997). Most of these studies focused on preparing leaders' networks in all professions and vocations on a national basis. The concept of community empowerment through active networking roles was emphasized in order to encourage and strengthen community potential to develop activities continuously and sustainably. However, no follow-up studies have documented the progress of these community projects.

There were three master theses completed that studied the roles of community organizations in the central region (Puangtong, 2001; Sooksand, 1999; Parittravadee, 1994). All of them were Buddhist temples and monks who took the role of health care providers, including spiritual healing and counseling for PLHIV and their families, by using temples as hospitals. These studies found that the model of having monks bridge understanding between PLHIV and other community members was too weak to build up positive relations among them. Also, some HIV/AIDS shelters located in temples were rejected by the communities. Hence, under the community pressure, the real social action by the religious sector in supporting HIV/AIDS networks was not effective in the central region communities.

Another three theses showed that family members' knowledge about HIV/AIDS and attitudes towards PLHIV had improved since 1994 (Jaruwat, 1997; Mohammad, 1998; Charoenpatpason, 1994). The acceptance and readiness to shoulder responsibilities of home care were increasing as well, despite the anxiety and concern of being "discovered" as AIDS families.

Another group of three theses studied the health care system and focused on the quality of care of formal health care providers (Eggpunyakul, 1998; Seongsatra, 1999; Chandee, 1999). The result brought out interesting as well as unexpected findings that there was still a lack of knowledge, understanding, and counseling skills among health-team workers, though there were signs showing improvement. Additionally, constraints of budget and ineffective collaborations among care units in the referral system also greatly affect the quality of care.

In conclusion, these research papers and theses showed that "family" is the most promising source of care for PLHIV. The long-term potentiality in the form of knowledge and skill on home care was seen to be possibly quite adequate in practice. And lessons learned were perceived to contribute to a better quality of care in the future under certain conditions, such as the improvement of health care supported by governmental organizers and NGOs, better understanding and attitudes towards PLHIV among community members, health policy and budgeting on AIDS care that really responds to the needs of PLHIV and their situation.

NGO study

Evidence for this section of the paper was drawn from a literature review of NGO materials such as reports from seminars and annual reports, a situation assessment through participatory observation of NGO activities on home and community care in Bangkok and Nakhon Pathom, discussions with NGOs delegates and PLHIV, and informal interviews on the telephone with NGO staff.

In the central region of Thailand, especially in Bangkok, there are quite a large number of medium or small NGOs focusing on AIDS, some of which work on AIDS only and some have other activities as well. Nineteen of these organizations were included in this study (see list of NGOs in appendix). Each NGO has different objectives, concepts and plans of activities. One interesting finding was that each of them was working independently, with little network collaboration. Four major themes were found: community development, social development, public health, and humanitarian aims. Despite these differences, two kinds of main activities are commonly performed: activities for supporting home care for PLHIV and health education

campaigns for disease prevention in groups seen to be at risk.

Activities supporting home care include volunteer training, home visits to assist family home caregivers, psycho-social support, financial support, emergency shelter provision, and coordination with health care referral systems or hospitals for treatment at critical stages. All these activities mainly serve supportive roles. The main care provision is performed in forms of self-care or family care. Hence, the achievement of NGO programs depended in part on effective support and a community approach to reduce social stigma towards PLHIV.

Factors noticed as determinants of the success or failure of home and community care performed by NGOs were as follows:

1. For confidentiality, members of self-help groups or NGO recipients usually were not regular residents of the community in which the NGOs offices were situated.
2. Inadequate knowledge of health and of care among NGO staff and volunteers limited the ability to help the PLHIV.
3. Socio-cultural differences between urban and rural communities affected the acceptance of having PLHIV cared for at home or in the community. Normally, PLHIV received more acceptance in rural communities than in urban ones. As described above, the socio-cultural context of urbanized areas, especially in the central region, include individualistic, self-centered, independent and materialistic values. All these characteristics made PLHIV have difficulties in self-adjustment in coping with stresses associated with living with AIDS, such as depression and confronting discrimination from relatives, neighbors, friends, and colleagues. In some cases these resulted in refusal to seek help from health professions or NGOs staff and volunteers. Therefore, experienced NGO staff and volunteers with better approach techniques had greater success in these areas than unskilled ones.
4. Limitations in perspective towards AIDS and related problems among NGO staff also affect the operating paradigm and activity performance. It is clear that most NGOs perceived knowledge as the most important determinant to approach PLHIV and help the community to accept PLHIV. But, from various experiences reviewed for this study, attitudes and psychological factors, such as being shamed or having family members be discriminated against by neighbors or relatives, played a much more powerful role than knowledge.

Knowledge-centered programs and activities thus sometimes misdirected the programs from their objectives of meeting the needs of PLHIV. Victim-blaming bias also brought a negative result to the projects when not addressed directly. Consequently, some staff and volunteers could not keep their spirits up to provide effective support for home and community care for PLHIV.

5. NGOs' management process in terms of inefficient perspectives and mechanisms for problem analysis and problem solving are factors that cause limitations in supporting home and community care. Other constraints and problems confronting NGOs' long-term performance were their limited resources in terms of financial support, human resources, vehicles, medical equipment, educational media, and academic support.

Case studies

Case studies drawn from communities in the central region were conducted to obtain further insight in addition to the documentary reviews. Altogether, ten cases (1 monk-healer, 5 female patients, 3 male patients and 1 gay man patient) were purposively selected from a variety of areas in the Central region: Two adults AIDS patients from a hospital in Bangkok (1 male and 1 female), a couple of spouses with AIDS recommended by NGO in Nakhon-pathom province, a middle aged female patient recommended by NGO in Singburi province, a couple of patients in Pattumtani province recommended by the temple hospital in Angthong province, a middle aged female and a gay-teenage patients and a monk-healer in a temple hospital in Angthong province. These case were indepth-interviewed and home-visited by the research team.

The results of these case studies confirmed some of the problems and limitations of home and community-based care in the central region that had been identified. The main constraint to effective care was the social stigma and discrimination toward PLHIV, perhaps exacerbated by the central region's stronger individualism, urbanized middle-class life styles, and looser social supporting network. Consequently, the case studies found mainly home or family care was being reliable. Compared with male patients, females were found to get less attention, sympathy and psychological support from members in their spouses' families. Hence, the immediate family or nuclear family was the major unit of care provision. In general the case studies revealed that within the extended family, HIV/AIDS was still a secret that should be definitely kept confidential. In some communities, people refused to contact, communicate or even to sell merchandise to PLHIV. These social sanctioned behaviors left PLHIV and their families to struggle alone with the care burden.

PLHIV also sought help and care support from self-help groups sponsored by NGOs outside the communities, including medical care and counseling support from hospital staff. Family or home care was being provided by PLHIV family members with a limited knowledge of care, and the quality of care was inevitably questionable. However, the home-based psychological, social and spiritual care towards PLHIV was reported to be mostly fulfilled from a holistic care point of view. Most families tried their best to care for the PLHIV at home, while the community discrimination was locked behind the house-doors. But this self-protecting behavior also made a barrier to keep PLHIV and families far away from getting access to NGO and government health care services and support. For this reason effective supporting networks were limited in their ability to meet the caring needs of these AIDS patients.

However, one positive community-based care program in a special form was recognized among these case studies. In several cases, care was provided through the social network of the wider extended family. Yet family members tried to keep the confidentiality of the PLHIV from outsiders: the formal health care service system, researchers, other villagers who were not family members, etc. To outsiders, the "small community" of extended family members tried to deny the fact that they kept PLHIV with them. On the other hand, besides health care, they supported the PLHIV at home with food, social activities, interpersonal relations, psychological support and a warm living atmosphere. This phenomenon was found in the less urbanized communities in the central region, outside of the capital city area of the province. This finding might lead to a hypothesis for further study: that the urbanized middle-class life

style and behaviors which have been firmly established since the Second World War have greatly affected the potentiality of home and community care for PLHIV in the central region of Thailand. Similar findings are also found in Natsupa's longitudinal study on development of Thai communities (Natsupa, 2010).

Another finding was the significant role of the temple and other religious organizations as medical practitioners (using traditional medicine) and spiritual healers for PLHIV and their families. This showed that, like in other regions of the country, monks and temples have served as practical caretakers for those suffering from illness, although as mentioned earlier some temples were rejected by community members and had to help PLHIV under great social sanction pressure from both inside and outside communities. However, such sanctions appear to be lessening in some localities as public health education about AIDS has become more effective in the past decade as reported in a study of five cases in the community near a Temple hospital in Angthong province (Puangtong, 2001).

Conclusion and Recommendations

The increasing morbidity and mortality of HIV/AIDS in the central region of Thailand means that home and community-based care is not only critically needed but also an essential strategy to help develop a better quality care system. For this reason, families need help to become prepared to provide this care. Support is needed for intellectual skills, caring skill readiness, having knowledge about care, developing a sympathetic attitude towards PLHIV, learning how to carry out caring tasks and dealing with the stress and burdens of care.

This challenging mission needs the integration and collaboration of all stakeholders, including PLHIV and families, GO and NGO staff, community members, local government organizations, the health care service system and policy-makers at the macro-level of all sectors in the country.

The definition and boundary of home and community-based care should be extended to cover the real social structure and interaction in the socio-cultural context of the central region. This is a specific context of urbanized lifestyles, ideas and practices that include individualism, small circles of social and interpersonal connections, loose family ties, a high level of self-protection, etc. Self-help groups that maintain confidentiality should be considered the most practical form of community-based care. The meaning of "community" may include people's real sense of belonging rather than the geographical or place-based meaning.

The documentary review of research reports and theses, together with discussion with NGOs and in-depth interviews with PLHIV, confirm the significant role of home-based care. The specific characteristics of the central region's urbanized socio-economic and cultural context are important factors to be considered when approaching PLHIV and their families, along with health promotion and disease prevention, medical care strategies and quality of life. A clear, open-minded paradigm with effective strategies and policies that fit with the socio-cultural context of the central region should be addressed and promptly taken into action.

The strategies and operational mechanism in supporting home and community-based care are suggested as follows:

1. Owing to the special socio-cultural traits of individualism and the low acceptance of the community towards PLHIV, home-based care should be the first and most important priority of care provision. Hospitals or other hospice form, such as care provided by temples, religious organizations, and NGO shelters may be reserved as the last choice or in an emergency or terminal situation.

Self-help groups among PLHIV supported by NGOs or conducted by governmental hospital staff are also needed and appreciated by PLHIV and families. Home visits provided by the formal hospital health team that are not well-prepared are less preferred since they may bring the consequence of lost confidentiality, social stigma and discrimination towards PLHIV and their families. Self-help groups should be adequately provided with sufficient financial support, especially transportation expenses and the like.

2. Effective collaborations among partners or stakeholders among the caring set of GOs, NGOs, community members, PLHIV and families should be strengthened through principles of equity, respect for others, fully active participation, and reasonable and sensible practices to build understanding of home and community care.
3. Innovative and interactive channels for building up communication networks among health professionals in care service units, PLHIV and their families and self-help group members or volunteers should be set up in order to provide active participatory communication among these people, on the basis of trust, confidentiality, convenience, and easy access in an urban lifestyle. Channels such as the mobile phone and cyber space such as Facebook are preferable for young urbanites since face to face communication may be refused.
4. Knowledge, experience and lessons learned by PLHIV and families should be shared with support for speaking out in their own words. The PLHIV voice should not only be listened to but also be extended, in order to make the public hear and understand PLHIV's needs.
5. Strategies supporting home and community care should be developed and placed into action, such as searching for the real needs of PLHIV and caretakers at home, empowering them with care knowledge and competency, supporting them to develop their self-esteem and to take more active participation in community and social life, preparing them to have new jobs for family income, developing a more appropriate health insurance system, allowing for tax-exemption for the home caretakers, etc.
6. Local community governmental organizations and members should be urged and empowered to take more active roles in setting local or community supporting systems for health promotion, HIV/AIDS prevention and home care in their own communities. These community organizations should be concerned and be responsible for members' well-being, including PLHIV and families. They should establish or acculturate a caring culture and practice in the communities by focusing on citizenship, human rights and humanistic care, through the concept of "To stop AIDS by caring for people with AIDS".

7. The National Health Policy and Universal Coverage system should clearly set up criteria for HIV related health care supportive measures. This should not only provide low-cost vaccination and treatments for health problems due to HIV infection, in order to support PLHIV in both situations of hospitalization and caring at home, but should also address financial support for health promotion activities and for improving PLHIV' quality of life, such as a monthly allowance for transportation to health care service for health follow up.

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Appendix

List of NGOs studied

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| 1. ACCESS. Bangkok | 2. Mercy Centre |
| 3. Siam Care | 4. Thai Business Coalition on AIDS. (TBCA) |
| 5. CARE | 6. Thai Red Cross |
| 7. The Sunshine Friends Association | 8. Candle Light for Life's Club |
| 9. Association for the Promotion of the Status of Women | |
| 10. The Planned Parenthood Association of Thailand | |
| 11. Duang Prateep Foundation | 12. Baan Pak-Jai Program |
| 13. Power of Life (WHISTLE HOME) | 14. Wednesday's Friend Club |
| 15. Wat Cheung-wai | 16. Wat Nong Sam-pran |
| 17. Bhan Ka-Lank, Suan Santi-tham | 18. Ban-Cheuan Group |
| 19. Thammarak Foundation | |