

**IMPROVING HEALTH CARE FOR HIV/AIDS IN THAILAND:
LEARNING FROM THOSE WHO SUFFER**

The seal of Mahidol University is a circular emblem. It features a central blue circle containing a golden chedi (a traditional Thai Buddhist stupa) with intricate carvings. Surrounding the chedi is a golden border with Thai script. The outermost ring of the seal is also golden and contains the university's name in Thai script.

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Thesis
entitled

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Duangkamol Wattradul

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Thailand is confronted by a rising number of AIDS patients and increasing serious demands for care and social support. The national AIDS plan has addressed the policy for the prevention and alleviation of AIDS; however, persons with HIV/AIDS still suffer with their chronic health status. To develop a healthcare policy appropriate for persons with HIV/AIDS, their experiences in accessing healthcare and voices of healthcare needs are deemed important guidelines to improve healthcare systems.

The purposes of this study were to describe the experiences of persons with HIV/AIDS regarding access to the healthcare system and to generate recommendations for a model of healthcare services. The study was a qualitative narrative study with a low-income sample of 30 females and 20 males with HIV/AIDS who shared experiences of health care access during in-depth interviews. Field notes were obtained for observing the contexts. Data was collected in public healthcare settings in five different parts of Thailand.

The results showed that many of the interviewees suffered limited treatment and care, sub-standard healthcare environment, and unequal healthcare coverage that impeded equal access specific treatments such as anti-retroviral therapy and continuity care. Sufferers said that factors that hindered their access to healthcare and community support were healthcare provider prejudice, personal weakness, and social discrimination. Factors that helped them to access healthcare were good information and healthcare systems such as Day Care and specific clinics for anti-retroviral therapy. They established family support and networks to gain access to good healthcare. They benefited by joining HIV/AIDS clubs which maintained their self-development, and gave them a voice to express their demands for proper healthcare. They said that their main health care needs were promotion of good health, prevention of opportunistic infection, equal access to standard care, and anti-retroviral therapy without discrimination. To promote access to continuity care, an effective referral network, adequate and qualified healthcare providers, universal healthcare coverage, and consumer protection were required.

The results of the study provide evidence and insights into how to improve the healthcare system for people with HIV/AIDS. Health policy with equity and quality access to care and treatment for people with HIV/AIDS is also elaborated.

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ประเทศไทยประสบกับการเพิ่มจำนวนของผู้ป่วยเอดส์และความต้องการทางด้านการดูแลและความช่วยเหลือทางด้านสังคมเพิ่มขึ้นอย่างรุนแรง ถึงแม้แผนเอดส์แห่งชาติที่ผ่านมาได้มีนโยบายเพื่อเป็นแนวทางในการป้องกันและลดปัญหาผู้ป่วยเอดส์ แต่ผู้ติดเชื้อ HIV/AIDS ยังมีความทุกข์ยากกับสภาพร่างกายที่เจ็บป่วยเรื้อรัง ดังนั้นการศึกษาประสบการณ์และความต้องการในการเข้าถึงบริการสุขภาพในผู้ป่วย HIV/AIDS จะได้แนวทางที่สำคัญในการจัดทำนโยบายเพื่อปรับปรุงระบบบริการสุขภาพสำหรับผู้ติดเชื้อ HIV/AIDS การศึกษาครั้งนี้มีวัตถุประสงค์เพื่ออธิบายประสบการณ์การเข้าถึงบริการสุขภาพ และศึกษาข้อเสนอแนะในการจัดทำรูปแบบบริการสุขภาพสำหรับผู้ติดเชื้อ HIV/AIDS โดยใช้การวิจัยเชิงคุณภาพจากการเล่าเรื่อง (Narrative interpretative) ในกลุ่มผู้ให้ข้อมูลที่มีรายได้น้อยผู้หญิง 30 ราย และผู้ชาย 20 ราย เก็บข้อมูลโดยการสัมภาษณ์เจาะลึกเกี่ยวกับประสบการณ์การเข้าถึงบริการสุขภาพและบันทึกภาคสนามในการสังเกตบริบทในสถานบริการสุขภาพต่างๆ ใน 5 ภาคของประเทศไทย

จากผลการวิเคราะห์ข้อมูลเชิงพรรณนา (Narrative Analysis) ผู้ติดเชื้อ HIV/AIDS ได้อธิบายความทุกข์ยากในการเข้าถึงบริการสุขภาพว่าเกิดจาก ความจำกัดของโครงสร้างในระบบบริการสุขภาพได้แก่ ความไม่ต่อเนื่องและไม่เพียงพอของการให้บริการ ข้อจำกัดของการรักษาดูแล การขาดมาตรฐานในการจัดการกับสิ่งแวดล้อมในระบบบริการสุขภาพ และความไม่เท่าเทียมในการใช้สิทธิในระบบสวัสดิการสุขภาพ ซึ่งขัดขวางการเข้าถึงความเท่าเทียมในการรักษาเฉพาะโรคด้วยยาต้านไวรัสเอดส์และการดูแลอย่างต่อเนื่อง ปัจจัยที่เป็นอุปสรรคในการเข้าถึงบริการสุขภาพและความช่วยเหลือทางด้านสังคม ได้แก่ การเลือกปฏิบัติของเจ้าหน้าที่สุขภาพ ปัญหาทางด้านสุขภาพและปัญหาทางด้านเศรษฐกิจ รวมทั้งการถูกเลือกปฏิบัติจากชุมชนและสังคม ส่งผลให้ผู้ป่วยได้รับบริการที่ไม่มีคุณภาพ รวมทั้งได้รับความไม่เท่าเทียมในการเข้าถึงแหล่งช่วยเหลือทางชุมชน ปัจจัยที่ส่งเสริมให้ผู้ให้ข้อมูลเข้าถึงบริการสุขภาพได้แก่ การได้รับข้อมูลและเข้าถึงแหล่งบริการสุขภาพที่เหมาะสม ได้แก่ การดูแลสุขภาพกลางวัน คลินิกเฉพาะโรค ซึ่งช่วยส่งเสริมการเข้าถึงยาต้านไวรัสเอดส์ การสนับสนุนจากครอบครัวและเครือข่ายทางสังคม การเข้าถึงชมรมผู้ติดเชื้อ HIV/AIDS ทำให้มีการพัฒนาและสามารถดูแลตนเองอย่างต่อเนื่อง และเป็นผู้ตัดสินใจเพื่อเป็นประโยชน์ต่อกลุ่มกลุ่มตัวอย่างต้องการการมีส่วนร่วมและคาดหวังให้มีบริการสุขภาพที่ส่งเสริมสุขภาพและป้องกันการติดเชื้อฉวยโอกาส และต้องการความเท่าเทียมในการเข้าถึงมาตรฐานและการรักษาด้วยยาต้านไวรัสโดยปราศจากเลือกปฏิบัติ โดยต้องการผู้ให้การดูแลที่มีคุณภาพและเพียงพอ มีบริการที่คุ้มครองผู้บริโภค มีความครอบคลุมของค่าใช้จ่ายในการรักษาเพื่อส่งเสริมให้ผู้ประสบความทุกข์ยากเข้าถึงการดูแลรักษาอย่างต่อเนื่องและเข้าถึงเครือข่ายการรักษาอย่างมีประสิทธิภาพ

ผลการวิจัยนี้ได้ให้ข้อมูลพื้นฐานและให้ความเข้าใจอย่างลึกซึ้งในการพัฒนาระบบบริการสุขภาพสำหรับผู้ติดเชื้อ HIV/AIDS สามารถนำข้อมูลด้านความต้องการในบริการสุขภาพของผู้ติดเชื้อ HIV/AIDS มาเป็นข้อเสนอแนะจัดทำรูปแบบการบริการสุขภาพที่มีคุณภาพ ครอบคลุมด้านค่าใช้จ่ายและมีความเท่าเทียมในด้านการรักษาและการดูแลอย่างต่อเนื่อง

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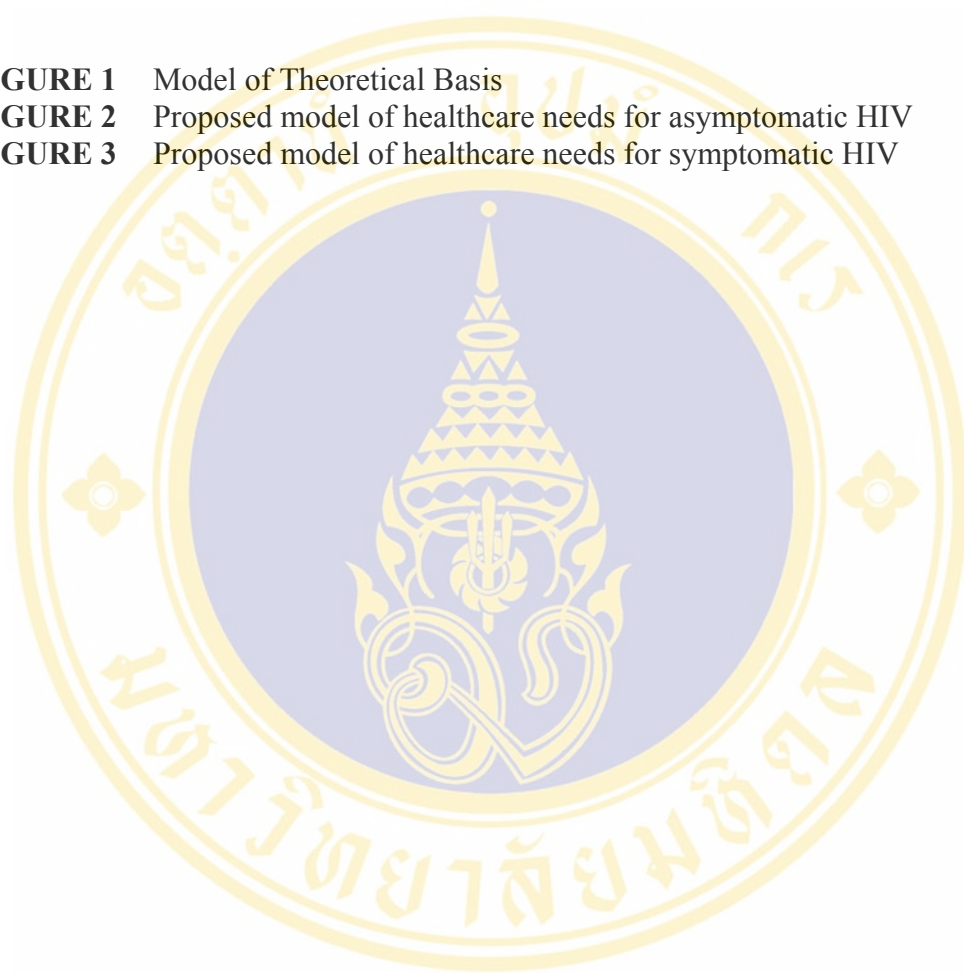
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CHAPTER I

INTRODUCTION

Background and Significance of the study

Healthcare policy is designated for specific purposes in the government mission and guideline in establishing healthcare systems, aiming to cover both resources and financial management and healthcare delivery for the people. The ultimate goal of the new healthcare policy is to improve and promote health of the general population and respond to people's expectations and needs. In addition, the healthcare policy should provide the system for financial protection against the cost of health and illness (World Health Organization, WHO, 2000a: 8). For this reason, healthcare policy is the guideline for stipulating the significant strategies for implementing practical health service to serve people. According to the former Thai National AIDS Plan, although there has been substantial success in HIV prevention efforts through a 100% condom campaign, close to 30,000 new HIV infection cases continue to occur each year. About 5.5% of people with HIV infection have developed progressive AIDS (55,000 cases) annually. The number of patients who subsequently died from AIDS is 289,000 cases (Department of Communicable Disease Control, The Division of AIDS, Thailand, 2002). This situation implied that Thailand is confronting with the rising numbers of AIDS patients and increasing serious demands for care and social support. Therefore, the new national AIDS policy needs evidence-based assessments to develop strategic plans to provide appropriate care and support for those living with HIV/AIDS and

their families. Furthermore, there should be the National AIDS Plan that provides suitable care and treatment for HIV/AIDS persons.

The primary strategy for prevention and alleviation of AIDS is social and behavior aspects. The former policy for HIV/AIDS care was not clear-cut and did not promote the strategic plan for practicable performance in order to treat HIV/AIDS patients seriously. Furthermore, the National AIDS policy does not associate with the law enacted under the Thai constitution in terms of civil and human rights to good health and to good quality of care from healthcare services (Criminal Court, 1998: 18). In the National AIDS plan (1997-2001), there is a policy to establish healthcare systems to promote health and provide medical care for people with HIV/AIDS. For example, improving healthcare services for HIV/AIDS patients in accessing equity and quality of care is implemented. In addition, there is a launch of the proactive strategy in order to promote health and provide community based care in the communities comprehensively and continuously. These strategies are operated with a holistic approach by the cooperation among government, private sectors, non-government organizations, communities, and people living with HIV/AIDS and their families including the inter-cooperative care between organizations (National AIDS Committee, 1997: 29). However, the policy of HIV/AIDS care by encouraging community-based care and supporting participation of people in communities is in the process of development and the model of care has not been well implemented due to ineffective healthcare services. For example, healthcare and services are provider-oriented, lack continuum of care, lack patients' problem assessment and follow-up, and lack effective cooperation of care and services between healthcare settings and

other organizations (Communicable Disease Control, the Division of AIDS, 1999: 4; Kantipong, P. et al, 1999: 5).

As the health policy for HIV/AIDS care is not associated with the legislation in the Thai constitution, the topic of the basic right of Thai people in their health causes concern. The regulation claims that the government has to provide quality healthcare services to people to ensure equal rights to access to standardized, effective, and affordable healthcare services. The poor and disadvantaged groups also have the right to receive the services for free of charge (Criminal Court, 1998: 19-20). However, the health policy for HIV/AIDS care does not cover straightforward medical treatment and care management of anti-retroviral drugs and opportunistic infection medicines. These effects create a problem for every person living with HIV/AIDS not able to have an access to medical treatment and healthcare services that are continual and available. In addition, these problems are not reflected and dealt with directly. Therefore, healthcare providers still provide symptomatic care. They do not have the perspective to control the progressive of AIDS symptoms, promote health, and prevent complication of the disease related to AIDS in order to improve people with HIV/AIDS' quality of life.

As for the revolution of AIDS treatment, AIDS has changed from an incurable disease to be a controllable disease. The trend and technology of treatment has also been changed to the use of medicines to reduce viral load and prevent opportunistic infection. People living with HIV/AIDS can increase the efficiency in their living leading to a decrease in the mortality rate and improved well-being of both the patients and their family. In addition, they can increase income and productivity of the nation (The White House, 2000a: 1-4). As regards the Thai healthcare policy, there is no

strategic plan to cover the treatment of anti-retroviral medicines to reduce viral load and some prophylaxis drugs used in preventing opportunistic infection. Furthermore, healthcare services provided for HIV/AIDS patients are not holistic, accessible, or continual. Service provision does not respond to the increasing health demands of a large numbers of HIV/AIDS cases, and this results in an impact on HIV/AIDS patients' continual treatment or access to healthcare. These factors bring about the hindrance in controlling and preventing the epidemic of AIDS. As a result, HIV infected people have the rapid progressive of AIDS, particularly opportunistic infection like pulmonary tuberculosis which easily spreads in communities. The report demonstrated that there were 42,455 or 27.5 % of AIDS patients who had pulmonary tuberculosis, leading to a high incidence of mortality rate (Communicable Disease Control department, Division of Epidemiological, 2000: 1). Consequently, the government has to spend more budgets to treat AIDS patients who have complications rather than provide the services to promote health and prevent opportunistic infection for people living with HIV.

The study of the National AIDS Plan in developing countries such as South Africa, India, Pakistan, and Thailand reveals that there is a lack of equality policy for HIV/AIDS treatment and care at a national level. Inadequate and unclear policies are major barriers and constraints to access effective care and treatment (AF-AIDS / ICASA, 1999: 5-9; The National AIDS Control Organization, 2002: 6-7; Khan & Hyder, 2001; 215-217; Nation AIDS Committee, 1997: 30; 2002:30-31). The policies lack tangible strategic plans regarding resources mobilization, planning, advocacy skill, and understanding for human right issues to increase awareness on healthcare providers and people in community. The issues of right to health and right to access to

equal treatment and care still lack the affordable, available, appropriate method to prevent AIDS progression and evaluation on strategic planning.

There is an example of a health policy for HIV/AIDS care in the country that has been successful in HIV/AIDS care. For example, in the U.S.A., the government has established a national plan and policy by promoting people with HIV/AIDS to have the capability to access the care and treatment in the early stages of the disease. Furthermore, the government establishes healthcare fundings of medical coverage by founding Medical Programs and The CARE ACT Program to promote and support patients with a low income and people who do not have healthcare security or insurance. For these reasons, patients with a low income can have access to the treatment of anti-retroviral therapy in the community healthcare settings (The White House, 2000b: 1-8). The cost effectiveness of using a combination of drug therapy of three medicines and Protease inhibitor including prophylaxis drugs for opportunistic infection leads to a decrease in the number of AIDS patients with complicated symptoms and people with HIV's ability to go back to work. The new drugs have sharply reduced the death rate by more than 70 % in the U.S.A. since the height of the epidemic in the early 1990s. In addition, the decreasing number of AIDS patients who have to be admitted in hospitals results in a reduction in hospital payment of less than 10 times which can save the money for hospital admission about \$10,000-\$16,000 per year (Pharmaceutical Research and Manufactures of America, 2001: 3; Freedberg, et. al., 1998: 130-136).

In the health policy of care and services for HIV/AIDS cases including the promotion of low-income people living with HIV/AIDS who do not have health insurance, access to standard treatment services will be available. They can have an

access to integration health services with treatment, prevention, promotion, and coordination between primary healthcare and community-based care. The quality of services is assured by controlling quality of care and improving the potential of healthcare providers in terms of continuous multidisciplinary teams. As a result, the mortality rate of AIDS patients have been reduced by 70 %, HIV infected persons who progress to AIDS have decreased by 20%, and new cases of HIV infection have been decreased from 150,000 to 40,000 cases per year. However, the health policy of care and services for HIV/AIDS cases is implemented more effectively in the high-income group of patients with healthcare insurance. The minority groups such as African Americans still have a higher mortality rate, or 10 times higher than that of White Americans (The White House Report, 2000: 2; Center for Disease Control and Prevention, 1999a: 1).

The studies related to access to healthcare systems in disadvantaged groups with HIV/AIDS such as minority, women, children, and low income people demonstrated access to anti-retroviral therapy (Anderson, 2000: 289; Abramowitz & Obten, 1998: 8-9). In addition, the knowledge based on the research explains the experiences of people with HIV/AIDS in utilizing healthcare systems. For example, there have been studies concerning factors that support or hinder patients in accessing health services in the community level (Tremble, et al., 1998: 510), the needs for healthcare services and social security, and access to healthcare services of AIDS patients who have Medicaid care (Rapkin, et al, 1998: 833-834), all of which are the foundation and important data in evaluating the cost effectiveness of the policy. The studies of HIV/AIDS experiences reflected and voiced the inequity of access to healthcare delivery. These studies are claimed to provide the solid data and significant

knowledge contributing to strategic implementation in order to alleviate and resolve AIDS problems. Moreover, the present policy is established to improve and promote people with HIV/AIDS to have a better access to healthcare systems. For instance, Global AIDS and Tuberculosis Relief Act of 2000 is established to prevent the problems of the epidemic of tuberculosis in HIV/AIDS. Disability Act is founded to facilitate the care and support for patients with chronic illnesses who are unable to work. This Act defines AIDS as a chronic disease. Thus, people living with AIDS can be supported by the Disability Act (The White House, 2000 b: 1-4; The White House Press Office, 2000: 2). However, the policy of alleviation of the inequity in accessing healthcare services for disadvantaged groups has not been practically evaluated in terms of effectiveness yet.

The evaluation of policy and strategic implementation of HIV/AIDS care and research of HIV/AIDS patients' access to healthcare will be important data leading to the establishment of a more effective health policy for HIV/AIDS cases. For example, in the United Kingdom, healthcare reform has been conducted and yielded a budget to support health promotion programs for HIV/AIDS instead of emphasizing cure for the disease. The health promotion program is successful in promoting safe sex behaviors, preventing exchanging needles among drug addicts, and promoting the care services in genital urinary clinics. Nevertheless, there is an example of a delay in blood test in pregnant women at the antenatal clinic, a lack of effective coordination of standard treatment of new anti-retroviral therapy, and an inequity of access to quality care and treatment (NAT, 1996; Associate of NHS providers of AIDS Care and Treatment, 1997; cited by National AIDS Trust, 1998: 3). These situations imply that although the United Kingdom has a health policy of healthcare coverage for all people, the cost

of care and services is high and the access to healthcare systems of HIV/AIDS patients is neither equal nor effective.

The review of a health policy for HIV/AIDS care in other countries has revealed that there is no concept and pattern of healthcare system that reveals the equity, accessibility, and effectiveness in order to develop the practical performance of care and services. Thus, Thailand can learn and establish a proper healthcare policy from the success and failure of healthcare services in other countries. This method may not be applied to provide an effective result. Some parts of the healthcare policy may be applicable, however, several factors that are different include social situation, socioeconomic, culture, and politics as well as geographic data leading to the different healthcare needs and expectations of people with HIV/AIDS. Recently, Thailand has suffered a great impact of a lot of problems such as social problems, economic recession, and the increase of health problems in the population (Pothisiri, P., et al, 1998: 1). Besides, the government has established the policy of AIDS prevention; it is in the process of developing the solution to serve and provide care for HIV/AIDS cases. In order to develop an efficient healthcare policy, some information and documents related to healthcare policy from many parts should be an important component. For instance, a national plan and policy should be associated with treatment and services of HIV/AIDS that are prosperous lessons in Thailand and other countries. In addition, the information that is not as important as the national AIDS and health policy but still has merits is the story of the experiences of persons with HIV/AIDS in accessing healthcare systems in terms of quality of care, equity, fairness of health finances, and the expectations and needs of care services (UNAIDS, 2000a: 107-115; WHO, 2000a: 31-35). The two sources of data from healthcare providers,

related to healthcare policy and client experiences, will contribute to significant data and will be the guideline in developing equality and justification of healthcare policy for people living with HIV/AIDS.

This study is aimed to generate the knowledge related to healthcare policy for HIV/AIDS care under the perspective of the critical theory (Habermas, 1971). The information and data of this healthcare system represent top-down policies such as healthcare policies and regulation or Act for HIV/AIDS care in Thailand and other countries, which will be critiqued for justification. On the other hand, the study of experiences of people living with HIV/AIDS in accessing healthcare systems in Thailand will reflect their voices from the bottom-up and advocate their right to equity of utilizing healthcare services. The synthesis of knowledge will contribute to the verification of data in improving healthcare policy for persons with HIV/AIDS that is in accordance with the Thai healthcare reform for the Thai population. The Healthcare reform goal is to encourage the Thai population and civil society to participate in enacting quality, equitable and adequate healthcare systems (Nitayarumphong, S. Ed. 1997: 192). Thus, this study is an illustration of how to learn and how to promote the utilization of healthcare services adequate and efficient for every Thai citizen, especially disadvantaged groups to ensure their equal right.

Research Questions

1. What are the existing policies of healthcare for persons with HIV/AIDS in Thailand?
2. What are the factors that hinder or facilitate persons with HIV/AIDS in gaining access to the healthcare system?

3. What features of healthcare policy will address issues of access for persons with HIV/AIDS?

Purposes of the Study

The purpose of the research is to contribute to the improvement of healthcare service delivery for persons with HIV/AIDS by learning from their experiences and views and influencing Thai healthcare policy makers in the process of National Healthcare Reform. The objectives of the study are as follows:

1. To study the Thai healthcare policies for persons with HIV/AIDS, and compare them with those of other countries
2. To describe the experiences of HIV/AIDS persons in accessing the healthcare systems and identify barriers for HIV/AIDS persons
3. To generate recommendations and identify the issues which health policy makers should consider for HIV/AIDS care and services to be applied in the national policy and health system process

Theoretical base

This study utilizes the concept of a postmodernist which is theoretically based on Habermas' Critical Theory. The original Critical Theory was founded on Critical Marxist's Theory (Neuman, 1997: 75; Stevens, 1989: 56). Habermas (1971) distinguishes three domains of cognitive areas in which human interest generates knowledge. This discovery knowledge determines relevancy and has claimed to be justified. The cognitive interests in societies are created from different aspects and interrelated between work, interaction, and power. They are categorized as:

1. Empirical /analytic knowledge or domain of work (Habermas, 1971: 70-90) which refers to the knowledge based upon the investigation and management problems by using technical rules to control and solve the situations and environment. This constructive knowledge contributes to empiric analytic science from practice in terms of scientific research domains such as Physics, Chemistry and Biology.

2. Practical knowledge (Habermas, 1971: 171-186) identifies knowledge generated from human interaction in society or communication action in order to understand an individual's experiences in societies. This practical social knowledge is produced to the knowledge in the areas of Historical Hermeneutic sciences, in particular the study of History, Phenomena, and Ethnographic Literature.

3. Emancipatory knowledge (Habermas, 1971: 274-300) identifies the inquiry which is interested in oppressed persons who are affected by the inequality and freedom from constraints and dominance in societies. The knowledge will be gained from the expression of discourse in terms of self-knowledge or self-reflection of the effects on dominance in society. The knowledge can be transformed to the improvement of society for oppressive groups. The knowledge of critical self-awareness is the way of knowing contributing to recognition of the correct reasons for their problems. The Critical Theory such as Habermas' Theory of Communicative Action is introduced to be the conceptual base of this study (Habermas, 1971: 309; Habermas, 1984: 199).

The objective of the Communicative Action Theory is to critique the society with both perspectives in the side of persons or groups who have injustice and the examination of conditions of power that influence individuals or groups. The theory is focused on understanding of human communication and the interpreted meaning as

reality of society that affects them. The analysis of problems in society with critical eyes and coordination of both sides creates the collaboration in developing solutions and transformation to the justification, equity, and fairness for oppressed people in society (Habermas, 1984: 216-222; Best & Kellner, 1991: 233-240).

In the Healthcare arena, there are a variety of disadvantaged groups who do not have equity in their basic rights such as women, children, low income people, and those living with HIV/AIDS. The perspective of Habermas' Critical Theory used in this study can generate knowledge and a way of actions that can help disadvantaged groups, particularly persons with HIV/AIDS who can gain the benefits. It can also be the guideline for better change in the structure of healthcare system for better health of disadvantaged groups. The ultimate goal of Critical Theory is to discover the way of knowledge and accomplishment to advocate and give a voice to persons with HIV/AIDS who are affected by the injustice and unfairness of societies such as health services operated by care providers who have power. The imbalance of power between oppression and dominance affects people living with HIV/AIDS' health and quality of life leading to social problems in the context of socioeconomics and politics on the macro level.

Critical perspective creates the critical context of the story that expresses and reflects the struggle experienced by people with HIV/AIDS in accessing the inequality healthcare system. While the analysis of the health systems and structures that influence HIV/AIDS can improve an understanding of the causes and effects on society socially, economically, politically and culturally that affect healthcare systems. The integration of the story and analysis of healthcare systems will enhance the

reformation of equity and justification of healthcare services that serve both healthcare providers and consumers (Stevens, 1989: 58; Stevens & Hall, 1992: 3-4).

Powers in the healthcare arena come mainly from two sources. Firstly, power comes from dominance in case of healthcare providers who practice and perform their function through a health policy organized by policy makers. The second power originates from oppressed individuals or groups through consumers who have struggled or successfully experienced utilizing healthcare services.

In the health system, healthcare providers have conservative powers and call themselves scientists, because they have authority to justify what is reality or knowledge. Therefore, they provide care for clients based on their scientific knowledge. In addition, healthcare providers organize the structure of the health system authorized by policy makers. In the constraint of economic and resources crisis, governments and policy makers try to manage the limited resources in order to maintain health and the quality of life of the Thai people. However, there is no healthcare system which is balanced between accessibility, equity of care, and holistic client-centered approach. Health systems should be established to solve health problems in a society and respond to the health needs of disadvantaged groups like HIV/AIDS patients. Recognizing clients' voices, views, and any aspect of the reality of healthcare contributes to create better healthcare systems for clients.

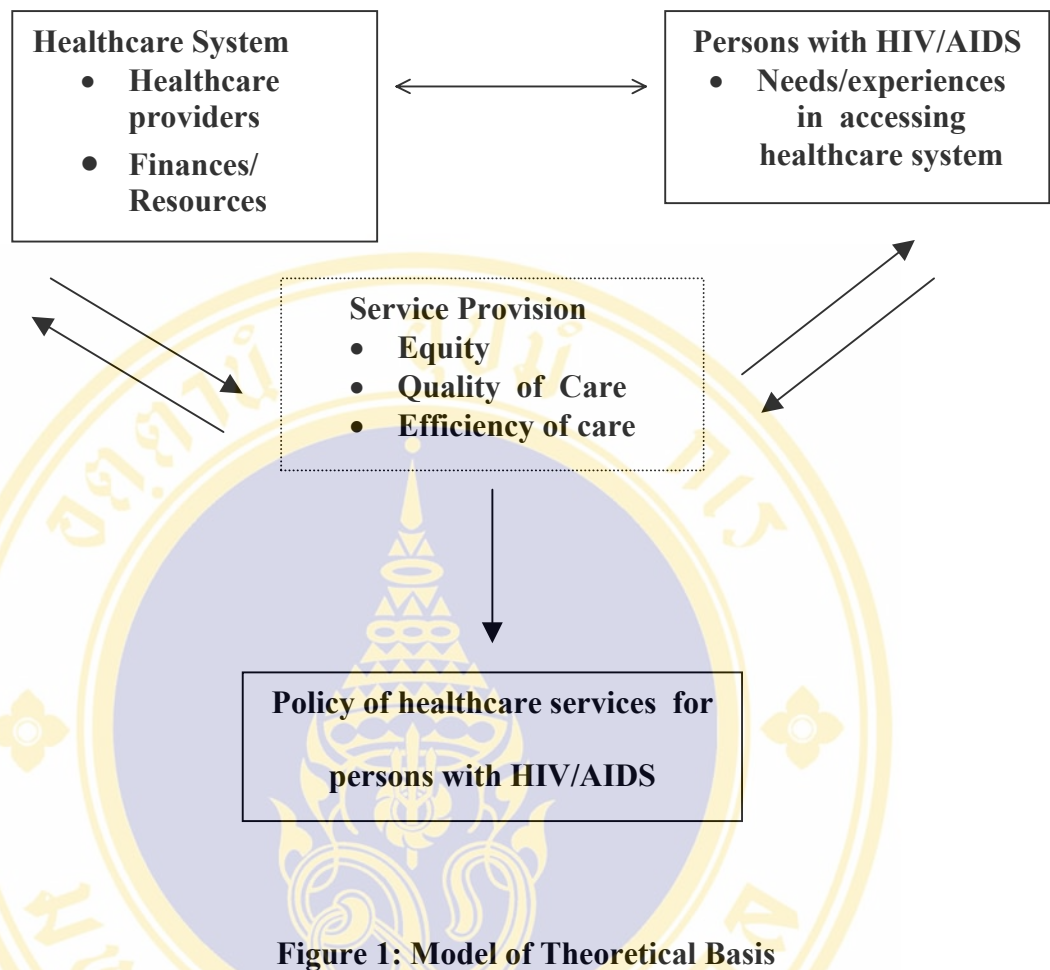
Critical perspective depicts and gains an understanding of persons living with HIV/AIDS who have several impacts on societies. Persons with HIV/AIDS who are a marginalized group do not have opportunities to voice their own problems in order to have equity and dignity in society. They perceive themselves as having stigma and are rejected by society (Alonzo, et al, 1995: 303). Thus, they have difficulties in receiving

equal rights as human beings because they are judged on their sexual behaviors prior to having the severe disease. As a result, their fair opportunity in access to services and resources in society will be affected. If they cannot work, they and their families will have a struggle in their living (McNeil & Anderson, 1998: S19-S26; McGrath, 1992: 63-79). HIV/AIDS infected persons will develop more health problems if they do not receive adequacy of care. They need more healthcare services to maintain their lives and improve their efficiency in their work.

Healthcare services are established by care providers who have authority or power. Traditional power is used because their knowledge can make a justification for what care services are provided for HIV/AIDS patients and how they are provided. This is not fair for HIV/AIDS patients and may not respond to basic rights of human beings, which everyone should have (Tan & Brown, 1994: S207). In fact, healthcare providers would like to provide efficient and quality care for every patient. However, the method of seeking and utilizing knowledge is traditional positivist resulting in lack of important data on the patients' part. Moreover, health policy and strategic plans established by authority which are top-down may not contribute to better health unless consumer perspective to balance provider interests is involved. The study of healthcare needs and voices from the bottom-up approach will shed light on the understanding of persons with HIV/IDS who have health impacts from healthcare systems. The essential information from the grassroots will be the solid data for policy makers to reconstruct the equality, efficiency and quality healthcare systems in collaboration with healthcare providers and persons with HIV/AIDS.

The advantage of this conceptual base with respect to policy development is that critical philosophy will promote and guide the healthcare profession away from their usual oppositional and dominant ways of thinking and acting. In addition, data obtained from the healthcare system structure, in particular health policy, will be critiqued and analyzed as an imbalance of their power. From this study, the voices of clients' problems in utilizing healthcare services can facilitate changes in organizations and enlighten health policy makers. The reflection of voiceless patients' perspectives and a balance of power with traditional authority can enhance improvement of healthcare services appropriate for the HIV/AIDS patients' needs.

This theoretical base will be tested for the first time in nursing study in this present study in Thailand. The outcome of the research will generate recommendations for a "model" of healthcare policy integrated with balancing power between persons with HIV/AIDS and traditional positivists. This research will contribute to the synthesis of possible and suitable policy based on the coordination and collaboration between the authority and consumers'.



Scope of the Study

The scope of this research is to address the recommendations and identify the issues which health policy makers should consider for HIV/AIDS care and services. The healthcare system for HIV/AIDS care in this study is healthcare services ranging from primary, secondary, and tertiary care provided in government healthcare settings in Bangkok and the central region, east, northeast, south, and north of Thailand. The healthcare policies related to HIV/AIDS care are integrated and reviewed for the documents of policy, regulation, and health systems in Thailand and other countries in Asia, Australia, America, Europe, and Africa.

Definition of Terms

Persons with HIV/AIDS refers to HIV infected persons, HIV infected persons with related illness, and people with AIDS who have opportunistic infections such as pneumonia (PCP), pulmonary tuberculosis, and/or AIDS wasting syndrome and who require continual care from healthcare providers in healthcare settings. In addition, they also need care that is provided by families at home.

Those who suffer refers to persons with HIV/AIDS.

Expected Outcomes and Benefits

1. The results of the project will be beneficial in developing a better healthcare policy such as healthcare services, universal coverage and a minimum package for HIV/AIDS patients and disadvantaged groups based on their healthcare needs.
2. The foundation knowledge will guide the health educational system in better preparing health professionals such as nurse practitioners, family nurses, and home healthcare nurses.
3. The findings can also be a guideline for planning a health policy to create the healthcare systems accessible to all with equity, quality, and efficiency of care involving patient centers to promote, and improve the well-being of persons with HIV/AIDS and families.

CHAPTER II

LITERATURE REVIEW

A review of literature related to the study of experiences of persons with HIV/AIDS in accessing the healthcare systems comprises 5 major issues. First, the healthcare policy for HIV/AIDS prevention and care in Thailand is analyzed. Second, the existing strategic plan of care and service policy for persons with HIV/AIDS is described. Third, factors contributing to establishment of healthcare services for people with HIV/AIDS are explored. Fourth, problems in the health system related to AIDS care are depicted. Finally, studies of experiences of persons with HIV/AIDS in accessing healthcare are reviewed. Literature review in this chapter enhances the understanding of situations and factors associated with healthcare systems for HIV/AIDS in Thailand.

Healthcare policy for HIV/AIDS prevention and care in Thailand

The national plan for prevention and alleviation of HIV/AIDS (1997-2001) focused on human development and environment. The strategic plan that emphasized applying health promotion and targeting medical care services included the following measures (National AIDS Committee, 1997: 29-34):

1. Developing and upgrading public services in order to more effectively support the potential of care-seekers to reform their behavior and to avoid the risk

of HIV infection. For instance, treatment for drug addiction and sexually transmitted diseases (STDs) and family planning would be improved.

2. Empowering the general public to manage AIDS and health problems themselves by ensuring full coverage of AIDS counseling and encouraging a wide distribution and used of condoms to prevent AIDS, STDs, and unwanted pregnancy.

3. Improving services, both curative and preventive, for persons living with HIV/AIDS by maintaining the health of the persons living with HIV and providing care in time of sickness through supporting network services and family planning services. In addition, families and communities should be supported to care for persons living with AIDS by enhancing their potential of care. Furthermore, enhancing the ability of staff should be done by providing ongoing training for staff to retain their present knowledge and to boost their morale in caring for people with HIV/AIDS.

4. Improving the access to health and medical care for people living with HIV/AIDS by collaborating with public and private organizations, communities, and families to promote community-based care for them. In addition, the quality, accessibility and efficiency of medical and health service systems should be enhanced by improving staff capabilities and referral systems among hospitals and others healthcare services in the communities. Moreover, alternative healthcare such as herbal medication, meditation, and nutrition therapy is encouraged for HIV/AIDS persons.

5. Promoting integration of counseling services in all public and private health facilities by improving the counseling skill of healthcare staff who provide care to risk groups of HIV or those who are already infected. Counseling services should be

integrated within other health services such as family planning and primary healthcare as well.

The national plan for prevention and alleviation of HIV/AIDS has been established by the Communicable Disease Control Department (1997) into 2 strategies. First, public health strategies comprise preventive measures and caring measures. Second, social strategy supports people with HIV/AIDS who have a social impact on AIDS. Preventive strategy is organized in association with the National AIDS Plan. The implementation of preventive strategy is effective. However, health promoting and targeting medical care services raised in the National AIDS Plan such as proactive services in promoting health and comprehensive care for persons with HIV/AIDS in communities are not tangibly conducted. In addition, the active strategy is not well developed and proceeded because care and services for HIV/AIDS are not demonstrated and guided by the policy makers. Therefore, the Thai National Plan for AIDS was analyzed and compared with other national plans, and it was found that the care and service policy in Thailand is lacking in the following points:

1. The Thai National Plan for AIDS lacks resource management of care and services for low income people to access early treatment and continuity of care such as granting a budget for women, children, and people living with HIV/AIDS who do not have healthcare insurance. In addition, there is no policy regarding funds for the public and communities to provide basic care and services, as well as integrating services and quality care as well as case management in community based care and/or primary healthcare (The White House, 2000b: 1-2; Australia National Council on AIDS and Related Disease, 1999: 145; Commonwealth Department of Health and Aged Care, 1999: 9; Advisory Council on AIDS; Canada Center on Substance Abuse, 1997: 1-18).

2. There are no measures to reform or establish a policy or act to assist people living with HIV/AIDS to use their rights to gain care and treatment such as by improving the Rehabilitation and Disability Act and assuring private insurance (The White House, 2000b: 5). In the Thai National Plan for AIDS, there is no fund to support care and services such as improving social security and health insurance and workmen compensation for people with HIV/AIDS because rehabilitation, anti-retroviral and expensive medication are not covered for HIV/AIDS laborers.

3. The health policy lacks clear-cut strategies in development and improvement of the healthcare providers' capabilities of caring for HIV/AIDS persons including training programs for updated treatment and care for physicians and nurses and other care providers in both the local health setting and the community health setting (Australia national Council on AIDS and Related Disease, 1999: 145; Commonwealth Department of Health and Aged care, 1999: 13). In addition, the measures for stipulating standards and guidelines of treatment, care, and services including enhancing the potential of healthcare providers in primary healthcare and the community are not well implemented. Furthermore, the policy of increasing health providers' distribution, in order to expand care services in communities, is not yet settled (The White House, 2000b: 6; Centers for Disease Control and Prevention, 2000: 40).

4. The strategy of assuring effective use of limited resources for HIV/AIDS care is not set up. In addition, the implementation of policies such as the cost effectiveness, quality of care, and healthcare assurance are not evaluated and/or followed to improve the next strategic plan (The White House, 2000b: 6-7).

5. The policy of care and services for HIV/AIDS lacks comprehensiveness and continuum of care such as establishing an ambulatory care system instead of an acute care system. In addition, the policy does not inform health providers of how to promote persons with HIV/AIDS access to care in the early stages of the disease. The strategy lacks practical coordinate continuum of care among the healthcare profession and collaboration of organizations in communities (Australian National council on AIDS and Related Disease, 1999: 145; Commonwealth Department of Health and Aged Care, 1999: 9).

The study of the National Plan and Policy for AIDS care concludes that that the AIDS care policy lacks clear-cut management of resources and manpower. The tangibles HIV/AIDS care and services are not set up. In addition, the models of holistic, continuum, and comprehensive care is not implemented practically. However, in order to make the suggestions and inform the HIV/AIDS care policy makers, investigators have to study the existing strategic plan of care and services policy implemented for persons with HIV/AIDS in Thailand and other countries.

The existing strategic plans for care and service policy for persons with HIV/AIDS

The existing healthcare services for persons living with HIV/AIDS comprises hospital-based care, community-based care, and primary healthcare. The details of care are described on the following issues:

1. Hospital-based care

The budget for public healthcare, health promotion, and AIDS prevention and control is about 76-64 % (1,098,662,500 baht) of the whole budget (National AIDS

Committee, 1997: 33-50). Most of the budget is used to develop the network of medical care and support for anti-retroviral therapy and opportunistic infection medication, as well as medical equipment for universal precaution. The budget for developing comprehensive care services for HIV/AIDS patients is only 1.5 % and that for counseling is less than 1%. The services provided for HIV/AIDS persons are pre- and post-counseling of blood testing, complication investigation, including outpatient care in special and general clinics. In general hospitals, persons with HIV infection receive no treatment and no monitoring for immunity. The treatment provided for symptomatic patients include anti-retroviral therapy and antibiotics for opportunistic medication. Inpatient services provide treatment for persons with HIV/AIDS who have a critical or emergency illness, in particular respiratory failure and fungus meningitis. Furthermore, day care service is delivered for developing treatment and social services for persons with HIV/AIDS and families (Kunanusont, C.1996: 1-6). Estimation of the number of HIV infected persons who develop AIDS is 6.8% annually. For this reason, bed occupancy rate has increased to 12%, and only 30%-50% of the patients who come to receive care would be admitted. The limitation of hospital-based care services is emphasized as follows:

1.1. High cost of care

Statistic records show that one person with HIV/AIDS has to pay approximately 3,000-120,000 baht per year for the care and treatment. The more the cost of care increases, the more severe the AIDS symptoms and the more immunity decreases. At the end stage of the disease, one AIDS patient has to pay about 60,000 baht per year for treatment and care when admitted to hospital (National Economic and Social Development Institute; cited by Shooprapawan, P. 2000: 203). The study

of the cost of care for treatment of symptomatic AIDS persons in hospitals was 40% higher than that of HIV infected persons who receive care at an outpatient department (Suwannagool, S. et al., 1997: 431-439). The budget loss in treatment of symptomatic AIDS persons for 60,000 baht per year is drastically higher because most of them have severe illness and could not work, resulting in lost productivity for the nation. In contrast, if health insurance services are provided and asymptomatic HIV persons spend about 30 baht per day (1,000 baht per month) for some anti-retroviral therapy and prophylaxis opportunistic drugs, they can work, have a high quality of life, and prolong progression to the AIDS disease.

In developed countries, the cost of care at hospitals in London increases with the severity of opportunistic infection diseases. For example, the cost of care for patients who have citomegalovirus is about 42,124 pounds (around 2,527,440 baht) per month (Beck, et al., 1996: 457). The treatment of anti-retroviral medication for AIDS persons is more effective when compared with AIDS persons who are not treated with the drug. Although the cost of care is high, the mortality rate has declined. However, in a country like the United Kingdom which has a healthcare coverage system, the cost of care is high in low educated patients who have no job due to a lack of social support and other facilities from health services and other places (Kupek, et al., 1999: 1433-1440).

1.2 Non-proactive services in healthcare setting

The treatment and care in hospital is decided and provided by healthcare providers. For instance, counseling, health education, psycho-social support, and social welfare are delivered. In addition, the services include health check-ups, treatment, and medicine for anti-retroviral therapy and such illnesses as tuberculosis

and pneumonia. These services are provided in general clinics and special clinics in developed countries which have small numbers of HIV/AIDS patients such as Japan, Hong Kong, and Singapore. These services are universal coverage since the HIV-infected detection in the early stage until the end stage (Japan Ministry of Health and Welfare, 1999; Singapore Ministry of Health, 2000; Choi & Lee, 2000: 11).

In the U.S.A., there is a high incidence of HIV/ AIDS persons. Health services provided for patients are in both special and general units. The study found that HIV/AIDS patients who receive care by specialty physicians and standard care by nurses in special units like dedicated AIDS units and Magnet Hospital have low mortality. In addition, HIV/AIDS patients are more satisfied with care for AIDS patients at Undedicated Units (Aiken, et al., 1999: 760-772). Another study found that providing care using a partnership care model comprises participation between nurses and HIV/AIDS patients along the process of health problem assessing and care managing as well as empowering the patients. The result of the study showed that patients were satisfied with the care, decreased the length of hospital stay, and reduced the cost of payment around \$ 1,590,384 in 1993 (Leenerts, et al., 1996: 37-49). However, care and services delivered at hospitals are not comprehensive because the care could not be continued to patients' homes and communities.

1.3 Non-continuity of services in the healthcare setting

The services offered at hospitals aim at prevention and treatment to large groups of people. There is no follow-up for patients and their family after discharge. Besides, the services are offered only at the center, not at a local level. Day care services are delivered in 42 central hospitals in Thailand. These services include medical check-ups, psychosocial services, and social assistance. For example, the

services can be vocational training, suggestions, and consultation for HIV infected groups and coordination with private sectors. From the assessment, it was found that the personnel have heavy workloads and there is a lack of experts for consultation. Even though the patients are satisfied with the services, they face difficulties in traveling costs to receive the services at provincial hospitals (Department of Communicable Disease Control, The Division of AIDS, 1998: 20-23).

In Thailand, the problems of hospital-based care are high cost of care and lack of systems in preparing the setting for caring HIV/AIDS persons effectively and continuously. The estimation of the budget in 1997 was that the government had to manage large budgets in drug treatment of about 1,777.20 million baht (Department of Communicable Disease Control, 1994; cited by Kunanusont, C. 1996: 3). In addition, the rising demand of beds for the new AIDS progression was approximately 3,400 beds, and the cost of care for one patient for a period of one month with three times of admissions was 300,000 baht per year (Lurkgarm, 1992; cited by Kunanusont, C. 1996: 4). As for counseling, the services did not cover all targeted groups such as AIDS patients, drug addicts, and pregnant women and teenagers. Furthermore, the treatment for HIV infected patients and AIDS patients was not sufficient due to the limited budget, medication, and standard practice (Department of Communicable Disease Control, The Division of AIDS, 1997: 24).

2. Community-based care

There is no practical measure for community-based care for HIV/AIDS patients in Thailand. This is exhibited in the National AIDS Plan Budget. Only 3.19% of the social service budget is earmarked to enhance the community proficiency for alleviating AIDS. However, only 2% (25 million baht) of the budget is set for local

health promotion and medical services, mostly emphasizing prevention rather than treatment and care (National Committee for AIDS Prevention and Alleviation, 1998: 24-32).

Most of the community-based care is administered in the area where a large number of people in the community are HIV infected, such as San Patong in Chiang-Mai province. The health services involve family members in caring of patients at home. This program is in cooperation with the Thai Red Cross Society and community hospitals. The program offers training to family members teaching necessary skills in caring for patients. The training is offered at hospitals for 1-2 days. There is also assistant groups visiting families at their homes. For instance, monks in the village offer mental support and meditation, while older women in the village are trained to offer care for orphans or children affected by AIDS and HIV/AIDS patients. This program is different from the Home Care offered in the West as physicians or nurses will not do home visits. The patients are taken to hospitals for treatment when they are severely sick (UNAIDS, 1999a: 1-5). This program greatly reduces the treatment cost at hospitals and encourages the family to take care of the patients at home. The drawback is the lack of quality and proficiency assessment for the treatment offered at home and the lack of practical follow up. It may also seem as if the burden is handed to the elderly people in the village. There is also a lack of assessment of the family's opinion and the participation of the community in offering continual care for HIV/AIDS patients.

Most community-based care in Thailand is administered by Non-Governmental Organizations (NGOs). The services offered are counseling, encouragement, social support, vocational funds, health education, home visits, recovery stays, and referral to

community health settings. These services are not aimed at home treatment. Very few service settings offer physical care, primary treatment, and nursing care. Besides, most of these community organizations are run by public health volunteers, monks, and associations of the HIV infected persons. The activities of these groups include consultation, consolation, meditation, home visits, coordination with community health services, and community facilities. The problems of community-based care are numerous. Patients refuse to disclose themselves. The community does not accept or offer cooperation. The persons who provide care at home lack practical knowledge. There is no medical equipment for conducting home visits. There are complications in managing and coordinating with government agencies (Phaosongrit, K. & Yachompoo, J. 2000: 40-97).

Ideal community-based healthcare must involve HIV/AIDS patients, their family, and people in the community. They must recognize and utilize the resources available in the community in alleviating AIDS problems. There must be coordination among nurses, social workers, and the leaders of the community in order to encourage care and facilities for patients (WHO: GPA, 1991; WHO, 1993). This also includes encouraging patients to gain access to continual and comprehensive care from the community in accordance to the culture and society (Bruno, 1999: 15-30). The following are characteristics of community-based care:

2.1 Variety of care for HIV/AIDS patients in the community

Community-based care involves prevention and care at the community level so that the care offered will be thorough, especially in heavily infected areas such as in Africa. It must encourage leaders and the people in the community to offer assistance to the HIV/AIDS patients. People will offer social

support and possess positive attitudes toward HIV/AIDS patients (Leonard & Khan, Eds, 2000: 1-13). In South Africa, the community and home-based care program provides counseling at community health centers. Volunteers and nurses do home visits and provide a home care package. The nurses also facilitate instructions and consultation on care to patients and their families. They refer patients to clinics, hospitals, hospices, social funds, treatment services, or self-help groups (Russell & Schneider, Eds, 2000: 19-41).

2.2 Health service system that meets HIV/AIDS patients' needs at different stages

Treatment services are provided at community health service settings with counseling, emotional and mental support, and primary treatment for HIV/AIDS patients. The services must be delivered by the health staff—physicians, nurses, related personnel, and volunteers in the community. Emergency shelter must be made available for needy patients, especially those who are also drug addicts (Gill, et al., 1998: 1-16). The expenses incurred from community-based care are usually lower than those from hospital-based care. HIV/AIDS patients who receive community-based care often recover more quickly and are able to resume their daily work sooner (Gill, et al., 1998: 4; The White House, 2000b: 4). Services that can be offered as community-based care for the final stage AIDS patients are:

2.2.1 Hospice home care. This service is administered for patients with 3- to-6- month expectancy (Local and National Hospice Information, 2000: 1; Hospice of North Central Florida, 2000: 1; Martin, 1998: 2). In the U.S., more than 90% of HIV/AIDS patients in their end stage of the disease are cared for at home by health staff. Physicians and nurses assess the health status, provide care to

relieve any discomfort, observe the symptoms, and coordinate with other related personnel such as pharmacists, nutritionists, social workers, or volunteers. These people will be able to offer assistance in the form of encouragement to the patients and family, offer advice on how to relieve discomfort such as pain, and observe and treat changeable signs and symptoms (Martin, 1998: 1-4; Hospice Foundation of America, 1999: 1).

Research on access to 500 hospice care programs out of 1,935 programs available in the U.S. indicated that most HIV/AIDS patients receive treatment at home. There are three home visits a week which last approximately 75 minutes per visit. The service aims at the relief of pain and symptoms through medication. The major problem is that the primary care providers do not have sufficient funds (Stumpf, 1995: vii). A qualitative research study on the quality of life of HIV/AIDS patients in the final stage at hospice settings revealed that AIDS patients had better quality of life when nurses, care providers, and relatives encouraged preparation of activities for the end stage in life (Amos, 1997: vii). Furthermore, it was also found that end stage patients required mental and social attention and support different from that of ordinary patients. The care providers must always coordinate with social support and develop hospice care programs such as training for their personnel and volunteers (Kovace & Rodgers, 1995: 49-65).

2.2.2 Residential hospice. This service setting offers care to full-blown AIDS patients who do not have a place to go and those from nursing homes. The care includes relief from pain and nausea, as well as mental and spiritual counseling by nurses and social workers. The cost is about \$235 per day, which is three times less than the cost at local hospitals. It is also less than the reimbursement

from Medicare/Medicaid. There was a follow-up evaluation after five years of administration which found that it had saved \$2.7 million from hospital programs and \$776,000 from the Medicaid programs. Thus, this program is considered to be very effective in terms of both humanity and cost (McCollum, et al., 1991: 402; 1992: 470).

In other countries, hospice care services are administered under the cooperation of government agencies, public voluntary groups, religious groups, and the community. These services can be found in Zambia, Uganda, Cambodia, and India. The treatment is mainly provided at home in accordance to symptomatic care, health rehabilitation, counseling, and advisory for family members. These activities are performed by physicians, nurses, and volunteers. It is also a chance for new personnel to acquire training (UNAIDS, 2000b: 14-15). However, this hospice care cannot keep up with the growing number of HIV/AIDS patients due to limited budget and personnel. In India, the number of final stage AIDS patients is greater than the capability of the hospice. Thus, the government is encouraging NGOs to organize more community hospice care for final stage AIDS patients (National AIDS Control Organization, 2000: 9).

As for Thailand, there is no healthcare facility for final stage AIDS patients that is administered by the government. There are eight hospice care centers: four administered by NGOs, 1 in Bangkok and 3 in the central region; 3 run by Buddhist temples; and 1 by the Christian Foundation (Department of Communicable Disease Control, The Division of AIDS, 1999a: 249-256). Most patients in the final stage seeking care and support from these hospices are those who have nowhere to turn to. The treatment provided at these places is not determined on the period of time, and the patients admitted at these service centers are not predicted on their expectancy

as those in the west (Martin, 1998: 2). Services at these hospices are free of charge. The care integrates modern medication, with herbal treatment, mental support, meditation and care until death (Dhammaraks Nives Project, 1997: 1). However, these services have not been properly studied, followed up, and/or evaluated in order to gain support from government agencies or private sectors in promoting continual community hospice care services.

2.3. Improvement on quality of Care

Case management can improve the quality of home-based care for HIV/AIDS patients. This involves monitoring, quality controlling, facilitating the treatment at hospital, continuing treatment at home, coordinating and referring to supportive networks, involving the health team and managing care with nurse specialists. This method enhances better quality of care at home (Nickel, et al., 1996: 91-99).

This corporate method of managed care and community based care reduces the amount of treatment time at hospitals and promises better satisfaction to patients, increases CD4, and decreases patients' depression (Huba, et al., 2000: 26-35). Patients with AIDS who received nursing with case management had a lower rate of death and lived longer than those who received treatment from hospitals alone (Sowell, et al., 1995: 24-31). Thus, case management is seen as an important method for integrating formal care (health personnel) and informal care (patient's family). Not only does case management offer relief for the patient's family from stress but also reinforces better access to the healthcare system in the community (London, et al., 1998: 481-503).

2.4 Health Promotion and Comprehensive and Continual Care

Home care managed by nurses encourages better relationships between patients and healthcare providers and better understanding of HIV/AIDS and care management at home for the care providers. The nurses' role is to encourage knowledge of the patients and the care providers in healthcare and access to quality health services. The patients and care providers can continually assess the quality of care, select proper home care services, and access social welfare systems in the community (Beker, 1999: 201-210).

Some studies in home care revealed that most HIV/AIDS patients suffered AIDS-dementia Complex, Toxoplasmosis, Wasting Syndrome, and Cytomegalovirus Retinitis, and these patients require frequent home visits (Melansee, et al., 1997: 27). The need assessment of patients who receive home care indicates that patients also suffer dyspnea, weakness, fatigue/lethargy, pain, ataxia, coughs, skin lesions, and memory deficit. They also have problems with insufficient food, homeless, limited funds, and lack of anti-retroviral medicine or medicine to protect them from opportunistic infections prior to the development of AIDS symptoms. Most of these patients will not have received any medication from their primary physician as the physician might not be specialized in AIDS (Hurley, et al., 1994: 33-40). Home care with the integration of multidisciplinary teams such as nurses and social workers that coordinates with a transprofessional model can reduce the cost as much as 8% and offers more holistic care than the conventional home care (Cherin, et al., 1998a: 55-72; 1998b: 55-72). The assessment of home care revealed that patients were more satisfied with their care, and their quality of life was also better (Foley, et al., 1995: 20; Huba, et al., 1998b: 17-26).

2.5 Health service management with limited resources

Community-based care has been administered in several developing countries such as Brazil, Kenya, Tanzania, South Africa, Uganda, and Zimbabwe. South Africa, in particular, has been very successful in this management as it is a cooperation of local and community health service settings and the government. The government offers funds and academic support. The administration is performed by voluntary private organizations such as nursing groups or people in the community. The preparation starts with preparing personnel for home care, arranging training for community care workers, and coordinating and monitoring the performances. The main problems are ineffective organizational management, insufficient knowledge and consultative skills in care providers, lack of financial remuneration for the volunteers, unacceptable attitudes toward HIV/AIDS patients, and lack of effective coordination between NGOs and government officials (UNAIDS, 1999; cited by Reproductive Health Outlook, 2000: 1-19; Russell & Schneider, Eds, 2000: 38-41).

3. Primary healthcare

Primary healthcare service is a local healthcare service aimed at outpatient services or out of hospital services. The services are provided and integrated with disease prevention, health promotion, care, and rehabilitation. This also includes emergency care and general treatments that do not require technical support for all age groups. The service involves coordination of the health teams and public participation. This health service is considered accessible for the general public as it meets the basic needs of the community (Office of Communications, HRSA, 1998: 1-6).

Primary healthcare has not been widely adopted in Thailand. Some research indicated that HIV/AIDS patients were better accepted by the community when the

community was involved in the community-based care program (Ramsoota, P., 1998: 241). In Phayao Province, there was a research study investigating the response of the community towards the HIV/AIDS situation in 1989-1997. Primary healthcare was adopted with the involvement of government agencies, the private sector, and people in the community. Health workers and NGOs promoted HIV/AIDS prevention in the community. They taught families how to take care of HIV/AIDS patients at home. This led to a greater realization of alleviation of AIDS, changes in preventive behavior, and reduction of the stigma on AIDS patients and support care for them. These changes allowed better care and treatment for HIV/AIDS patients resulting in better quality of life. NGOs also offered assistance to HIV/AIDS patients' families in caring for AIDS patients at home and provided vocational support. This study clearly demonstrated that community involvement can quickly alleviate some AIDS problems. The cooperation of government agencies, NGOs, and the community can greatly increase the potential of health service settings in offering comprehensive and continual care to HIV/AIDS patients and their families. This idea is gradually being adopted and applied to several areas in Thailand (Silarug, et al., 1999: 853; UNAIDS, 2000c: 8-11).

Primary healthcare is the closest level of health service to the community. People can be involved in the service, and it offers beneficial results to the community, including illness prevention and health promotion, especially for those with the chronic illness of AIDS. The general characteristics for primary health services should be:

3.1 Quality service for people with low income

Primary healthcare in the U.S. is for the needy groups of people such as minorities, females and children, chronic patients, and those who do not have social security and/or have low incomes. This group is comprised of about 35-45 million people (Agency for Healthcare Policy and Research, 1997; cited by Office of Communications, HRSA, 1998: 3). The services range from emergency care, mental health, oral care to treatment of substance abuse offered by multi-disciplinary teams of nurses, physicians, dentists, physical therapists, and pharmacists. The emphasis of the service is on the effective and proper service, differences of cultures, family as the center, and convenient access for people (Office of Communications, HRSA, 1998: 1-3). Primary healthcare for HIV/AIDS patients should include prevention, treatment methods, counseling, early detection, anti-retroviral medication, and prevention of opportunistic symptoms. This primary healthcare can decrease the rate of disabilities through the development of symptoms and increase the survival rate of patients (Sheffield & Paauw, 1997: 37-42).

3.2 Continual care in community health service settings

In Brazil, the Ambulatory Nursing Care is an external health service for HIV/AIDS patients who suffer Tuberculosis (TB). The service aims to encourage involvement of the patients and the family in treating TB through consultation, follow up, medicinal side effect monitoring, and evaluation of treatment. Forty-eight percent of patients in this program were successful in their treatment (Sinkoc, et al., 1998: 357).

There is also a Community Healthcare Worker Program (CHCWP) in Brazil which aims to prevent and control sexually transmitted diseases and AIDS at the

community level. Each team consists of one nurse and 30 public health workers. The team can offer services to 200-250 families in one month. They do home visits, offer consultation to pregnant women and the family, and refer patients to primary healthcare units. There are 775,200 families receiving services from CHCWP, and the program is extending its services to cover the whole country. It can effectively control the spread of AIDS and sexually transmitted diseases because information of the illnesses reach people with differences in cultural and social levels (Vasconcelos, et al., 1998: 886).

In Australia, the Broader National Public Health Sector Reform established Ambulatory Care in place of Acute Care Setting to offer access to the healthcare services for the HIV/AIDS infected aborigines. Coordinate continuum care is emphasized at the primary healthcare level. General physicians are trained, and case manager nurses are available so they can perform continual care to HIV/AIDS patients (Australian National Council on AIDS and Related Disease, 1999: 143-147).

Personnel in primary healthcare settings

Primary Physicians can be resident physicians or general practitioners who are on duty and provide treatment for HIV/AIDS patients in the community. Even though the morbidity rate among HIV/AIDS patients has been reduced and the survival rate has increased, HIV/AIDS patients have expressed that physicians lack expertise and have inappropriate attitudes and discrimination towards their patients. They select the patients they want to treat. This means complete access to treatment is not available for all patients, and opportunistic symptoms such as TB or pneumonia are likely to occur (Sheffield & Paauw, 1996: 1-10; Spradling, 2000: 2).

Nurse Practitioners (NPs) are key members in the health team for primary healthcare. They are considered primary care clinicians who provide nursing care and act as client advocates and case managers. They perform services so that the patients' physical and mental needs are met (Kirton, et al., 1999: 72). In the U.S., NPs provide care and treatment to patients who live in rural areas, make decision on treatment methods, perform treatment with consultation from HIV/AIDS experts, and offer consultation to patients and their family (Lewis & Miramonte, 1999: 39-42). A comparative research study indicated that NPs are a better option for HIV/AIDS patients than physicians in outpatient departments where the number of patients is high as they can collaborate better with physicians for more effective results of the treatment (Lehman, et al., 1991: 406).

In many countries, such as India, nurses take a very important role in providing continual health services in the primary healthcare level, especially among final stage patients. Nurses provide consultation and support health education to patients and their family. They encourage better life quality among patients. These nurses need continuing support on their training and skill development (Kipgen, 1998: 358). Provision of NPs in primary healthcare services promises coordination of service with cost effective results. It is a solution for many countries that lack physicians, have limited resources, and suffer a growing number of patients. The Netherlands, Taiwan, Botswana, Northern Ireland, and New Zealand are examples of these countries, which encourage more NPs. The Australian government even supports the role of nurse practitioners by passing legislature to validate the nurses' status (Sheer, 2000: 1-6).

In Thailand, nurses who perform services to HIV/AIDS patients in health service settings in rural areas are just technical nurses without practical knowledge of

HIV/AIDS. For example, they lack special knowledge in detection and treatment of complicated AIDS symptoms and AIDS counseling. In order to offer quality and cost effective service with limited resources for HIV/AIDS patients and their families, the potential care providers at the local level must be developed. They must be able to offer quality care to HIV/AIDS patients, manage health services for community to meet all the needs, and allow convenient access to these facilities.

In conclusion, healthcare delivery for persons with HIV/AIDS is in the process of development. There is no tangible healthcare policy and practical strategy implementation that are appropriate for HIV/AIDS. In order to solve these problems and establish complete, comprehensive, and holistic care for HIV/AIDS, the factors contributing to develop healthcare policies should be mentioned.

Factors contributing to the establishment of healthcare policy for people with HIV/AIDS

In order to provide comprehensive health service to HIV/AIDS patients and their families, a health service policy must be adopted.

1. Social and National Responses must be taken into consideration when setting policies to tackle AIDS.

1.1 Political will and leadership

The governments and the leaders of countries are the main factor in alleviating AIDS. They must illustrate their commitment and support in planning policy, setting funds, and allocating resources for implementation of the policy. The local leaders must also play an important role in motivating community responsiveness to the problems, participate in problem solving, and establish the

policy to achieve a policy plan. For example, the U.S. leader and the U.S. government respond to the AIDS problem and factors affecting HIV/AIDS patients and family. They have set policies and funds for this particular purpose. They encourage community-based care. Community, government agencies, and private sectors must be involved. This policy has led to a reform in the Health Rehabilitation Act which is more beneficial to chronic patients and HIV/AIDS patients. It also financially supports research in the alleviation of AIDS (The White House, 2000b: 2).

The follow-up on the National AIDS Plan indicated that Thai leaders and the Thai government realized that the AIDS situation was a national threat. The National AIDS Plan was adopted in accordance with the National Economic and Social Development Plan. Resources from both government agencies and private sectors were assembled, budgets were earmarked, and all agencies were encouraged to take part. For example, the 100% Condom Campaign encouraged 93% usage of condoms and reduced HIV infection among prostitutes by 23% (Rojanapiyakorn, 1999; cited by HIV/AIDS Resource in Asia, 2000: 7). However, an effective policy must be followed up, evaluated, and controlled so that the policy can be adjusted accordingly as there are 60,000 patients who are infected each year (WHO, 2000b: 22; Limpakanjanarat, K., et al., 1998: 23). A preventive policy should encourage continual treatment and easy access to health services from the beginning of the infection stage.

In some countries such as Bangladesh, Indonesia, Laos, the Philippines and Sri Lanka, the reported level of the AIDS epidemic is low because the governments are not concerned about the problem and there is no preventive method to tackle the spread of the disease. The number of HIV/AIDS cases is underestimated, and this leads to a limited budget set for the prevention and alleviation of AIDS

(UNAIDS/WHO, 2000: 24). In Indonesia, there were about 12,000-30,000 HIV infected patients who received treatment after the AIDS symptoms developed and died (Jakarta Post, 1996; cited by Regional AIDS NEWS, 2000: 1). However, the government reported in December 2000 that there were only 1,172 HIV infected patients and 452 AIDS patients (Indonesia Communicable Disease and Environmental Health, 2000: 4). As a result, the government is not able to set an appropriate policy to alleviate AIDS due to the lower number of AIDS cases reported.

1.2 People's awareness and social openness

People's perception and realization of AIDS and the openness of the society will lead to a better establishment of policies to tackle AIDS. People did not know much about AIDS when it first became an epidemic. Their reaction towards HIV/AIDS patients was one of fear and disgust. Therefore, campaigns on creating better knowledge and understanding about AIDS at every level in the community will lead to a better acceptance of the patients so that people will not fear or reject HIV/AIDS patients (UNAIDS, 2000d: 2).

Correct publication and distribution of information about the AIDS situation is also needed. In Thailand, there are publications on the spread of AIDS among prostitutes and the unjust treatment experienced by HIV/AIDS patients. This type of information creates sympathy among people toward HIV/AIDS patients. It would lead to better support on policies and measures to be taken for patients. This method is definitely better than preventive policies alone (AIDS captions, 1996: 5).

1.3 Policy assessment and sustained responses

Assessment of policies and results of implementation will allow better input for policies. In England, the assessment on the National AIDS Plan indicated

that some HIV/AIDS patients received substandard treatment and access to health services which were not for all. This was due to poor coordination of care and inequity of medication treatment in disadvantaged groups such as pregnant women and prisoners. In order to develop an appropriate national policy for AIDS, improvement on health services to meet the standard must be taken into consideration. There must also be policies that promote health and socially support patients. New treatment options must be offered. Besides, there must be an evaluation and monitoring on the treatment. Care providers must improve their potential, so they will be able to perform comprehensively and with continuum of care (National AIDS Trust, 1998: 8-9).

In some countries, patients are socially affected. Society refuses to accept them. There are insufficient health services for them due to the lack of personnel and resources. The solution to these problems should be social support for the patients and their family and encourage community participation in the alleviation of AIDS problems (National AIDS Committee, 1997: 1-8). Assessment of policies and strategic plans should be conducted thoroughly so that the policies will reflect and solve current problems.

1.4 HIV/AIDS epidemic and its social and economic impact

This epidemic affects society and its economy from macro to micro levels. It affects gross domestic product (GDP) significantly. In South Africa, more than 20% of the population are infected with HIV/AIDS. This reduces the national GDP by 2% (UNAIDS, 2000e: 19). In Asia, the GDP has gone down by 2-3%. It also greatly affects the enterprise level in developing countries. In Asia and Africa, HIV/AIDS patients quit jobs or switch jobs. Then comes the lack of workforce. Patients have to take time off due to their illness. Industry loses profit, and investment or production

becomes lower. Patients themselves lose their income. Government health service settings suffer from the limited treatment they can offer, and patients must turn to private establishments. This means higher costs for treatment that cut directly into family income. Many patients die sooner than they should. Children whose parents were affected by AIDS become orphans (International Labor Organization, 1999: 13; UNDP, 2000: 1-8). The analysis of these effects should be an important part in setting policy for each country. These policies can be seen in the policy for treatment for HIV/AIDS patients in South Africa where people have impact on AIDS and there is no healthcare coverage for the treatment (UNAIDS, 2000e: 20). On the other hand, the legislation reform and increased budget for HIV/AIDS preventive measures in Honduras are examples of the countries which can reduce economic problems related to AIDS successfully (AIDSCAP, 1999: 1-16).

1.5 Multisectoral and multilevel collaboration

This type of collaboration within government agencies or between the government agencies and civil society plays an important part in the achievement of the policies. The AIDS situation is very complicated and requires a great collaboration among government agencies. For example, the Ministry of Labor and Social Welfare should take part in planning policies to prevent and alleviate AIDS for laborers and set budgets for continuity of care and social support for the HIV/AIDS patients. The Ministry of Education can encourage prevention and alleviation of AIDS through sex and AIDS education for students, teachers, and parents. At the same time, the Ministry of Public Health can take charge in the follow-up on the spread of AIDS and offer quality healthcare services. Private sectors such as the mass media and NGOs can participate in this prevention and alleviation scheme by conducting follow-ups,

promoting policies, protecting human rights for patients and their family, speaking out for the patients, and suggesting any other policies to government agencies (UNAIDS, 2000d: 3; The UN Human Right System, 1999: 1).

1.6 Community-based participation

This participation means better understanding by the people in the community and their involvement in any supportive activities in preventing and alleviating AIDS or assisting the HIV/AIDS patients and their families. This participation will also lead to power of the people to request action from the government in dealing with AIDS. For example, there are HIV/AIDS homosexual groups in several industrial countries. Such groups are set up as organizations with networks in some other countries (Scott & Rosko, 1999: 1-8).

Community participation in the fight against AIDS also helps the government to realize the problem more clearly and set a proper policy to assist minorities in the community. In the U.S., African Americans are ten times more likely to be infected with HIV/AIDS. The Center for Disease Control (CDC) facilitates the community by offering financial support in prevention and alleviation of AIDS for the African American community. The Black Homosexual Community in New York offers assistance to couples, one of whom is infected, in preventing AIDS and/or counseling on drug abuse. In addition, the African American Teenager Assistance Community offers consultation on AIDS prevention and the practice of safe sex (Centers for Disease Control and Prevention, 1999c: 1-15).

As for Thailand, activities of this kind are flagship projects or research projects in widespread areas in the north. The management of these activities depends much on funds from the government or foreign organizations. There are some groups

or networks for HIV/AIDS patients, but the associations are inexperienced and administered on a small scale. Moreover, most of the members have low income and depend mostly on funding from the government or private sectors. Even though the family and the community start to accept patients more, they are still not able to take care of the patients at home due to lack of knowledge and economic support. The family and the community also suffer with financial burdens (Wattanaputi, C. 1996; Pornsiripong, S., et al., 1994; Krairurapong, S., et al., 1996). Some research also indicated that some communities are not ready to be involved or accept patients. This is because they lack efficacy in participation and do not want to take part in the problem solving process as they still did not know or understand AIDS. Therefore, the readiness of the community in alleviating AIDS must be taken into consideration when planning health policies.

1.7 Social and political policy reform

HIV/AIDS infection affects people physically and socially. These factors must be considered when planning a health policy. Most HIV/AIDS patients are females, children, and low income people. The impact can be seen in the inequality in human rights as education, economy, legislation, and access to the health and social services (The UN Human Rights System, 1999: 1-4). The solution to the problem is to force social and political systems to allow equal access for HIV/AIDS patients to health and social services. In the U.S., the reform in Civil Right Restoration Act allows HIV/AIDS patients to be admitted for treatment at nursing home type hospitals and other social services (The White House, 2000a: 1-4).

Education reform in Thailand allows complete access to educational services. This change can be considered as one long-term solution for the AIDS

problem. Promotion of education and vocational training for rural girls reduces the HIV/AIDS infection rate of girls in prostitution. There is also promotion of equality in education for women. Health service reform as it appears in the present constitution (1997) also indicates equal access to health services. For instance, Section 52 indicates equality of people in accessing standard public health services. The state must provide thorough and efficient service for people. The poor deserve to be treated without paying any expenses (Criminal Court, 1998: 16). Health service policies for HIV/AIDS patients must cover the rights stated in the constitution. Furthermore, HIV/AIDS patients must be able to access health services which are sufficient and with quality. The expense must be fair and appropriate. In brief, it is the state's and the people's duty in setting a policy that promotes equal access for HIV/AIDS patients to health services.

1.8 Learning from experience

Experience from other countries in HIV/AIDS dealing with prevention and alleviation must be considered when planning health service policies. Context, appropriateness, and practical achievement must also be considered. The experience learned from the program on prevention and alleviation of AIDS in Phayao Province can serve as an example for new health service management for Thailand (UNAIDS, 2000c: 4). However, to establish a healthcare policy that serves people's needs, information from the service receivers as to the patients' experiences and perspectives on quality of service, equality, accessibility, and healthcare expense and expectation of care should be part of the assessment and reform program for health services (WHO, 2000a: 31-35).

1.9 Adequate resource allocation

The availability of resources is also a major factor in planning health service policies. The U.S. government has policies in supporting early stage treatment, promoting blood testing for people, and offering preventive and treatment healthcare. The government pays as much as 13.7% of GDP for healthcare and medication (WHO, 2000a: 195). Combination drug therapy of three medicines and protease inhibitors help reduce the number of AIDS patients, and infected persons are able to go back to work. The quality of life is better, and the number of AIDS patients admitted to hospitals for treatment has decreased. The expense of anti-retroviral therapy is around \$10,000 to \$16,000 per year. This is ten times lower than the expense of treatment for AIDS patients at hospitals (Pharmaceutical Research and Manufactures of America, 2000: 3). This indicates that allotment of budgets is done on the priority of significance of problems, and long term plans for quality of life of HIV/AIDS patients are the main concern. This also greatly reduces the burden of families and society in taking care of dependent patients.

The allotment of funds in several developing countries with limited budgets is aimed at the preventive aspect especially in women and children. This is a long-term and promising plan. For example, there are policies on improving life skills for teenagers relating to safe sex, pregnancy prevention, and being free of drug. This also includes more effective systems on setting funds, managing resources, and carrying out organizational development and personnel development. However, the campaign on community involvement and local resource allowance is still conducted at low levels in developing countries (UNAIDS, 2000d: 20).

The Thai government spends its budget from the National AIDS Plan (1997-2001) on promoting strength in society and the family. This is in accordance with the 8th National Economic and Social Development Plan. More budgets were set for plans on AIDS prevention and alleviation. Emphasis was made on personnel, family, and community development. Psychosocial service was offered. The budget on health promotion and medical services was reduced as Ministry of Public Health had set a different budget to cover these services (Department of Communicable Disease Control, The Division of AIDS, 1998). However, the National AIDS Plan did not indicate the development for health service providers especially those working at the local and community levels. During the economic crisis, the budget on a preventive program was reduced. This led to an increase in HIV infection among pregnant women, drug abusers, prostitutes, and youths. There were 500,000 more orphans during this period (Kunanusont, C. 1999; Cawthorne, 1999; cited by HIV/AIDS Resource in Asia, 2000: 7).

2. International force and support

The spread of AIDS can be found in developing countries in Asia and Africa. There are 5 million people who are infected each year. It is expected that about 4.5 million people will die of AIDS each year, or about 75% of the HIV infected people (Social Link Production, 1998: 1). The impact of AIDS is not only on the patients and the family but also on economic and social systems. Personnel resources and the Gross National Product are affected. In developing countries, development of basic service systems such as health service and education is limited. Unskilled labor is prevalent, and HIV/AIDS patients are not treated equally. Also, human rights are violated, while health and social services are not accessible. However, many international

organizations are offering assistance in this matter. For example, the U.S.A. offers financial assistance to Africa for preventive programs and AIDS treatment. Funds are also spent on creation of networks and coordination on AIDS related activities (The White House, 2000a: 1-4; UNAIDS, 2000d: 5-6).

WHO, UNDP, and UNAIDS also reinforce many member countries with AIDS information to set policy on legislation, ethical and human rights for HIV/AIDS patients. Support is also aimed at personnel development, development of expertise, and creation of networks for AIDS related programs such as treatment, research, education, society, and the economy. It is an attempt to alleviate AIDS in developing countries especially among the disadvantaged groups (UNAIDS, 1995: 17-33; 2000e: 11-13; The UN Human Right, 1999: 1-4; UNDP, 2000: 1-8; Gupta, 2000: 1-8).

In many countries, their health service policies are influenced by the international organizations they receive support from. In India, for example, health service policies reflect the policy of the World Health Organization (WHO) (National AIDS Control Organization, 1999: 5). Thailand also receives assistance from WHO in setting up AIDS prevention programs. The Center for Prevention and Alleviation of AIDS was set up from the very beginning of the AIDS epidemic (1987). In 1990, the government realized the significance of the problem, and AIDS was emphasized in the national plan. The National Committee of AIDS Prevention and Control was established to regulate and set policies to reflect government policies. In 1998, a National Committee of AIDS Prevention and Alleviation was set to perform continual AIDS policy (Poolcharoen, V., et al., 1999: 108-122).

International financial support for AIDS prevention and control that Thailand has received is small by comparison to the government budget. This international

support has been reduced since 1994, whereas the government spending on the matter has increased considerably (Poolcharoen, V., et al., 1999: 96-98).

It was found that the leader and the government have raised AIDS to be a significant national problem. In some communities, people have accepted the problem and become involved in solving AIDS problems. Political changes and reforms are made; thus, they would be in accordance with health reform. Organizations, both national and international, have taken part in this policy reform so that policies would reflect and meet the needs of HIV/AIDS patients and limited resources. However, health problems related to AIDS care and the evaluation of the implementation for HIV/AIDS care and services are required in order to investigate the strength and weakness of the present healthcare policy and services for persons with HIV/AIDS.

Health system problems related to AIDS care

The health service system in Thailand consists of healthcare settings, financial and human resources, and service provisions (Guideline for the Analysis of Gender and Health, 2000:15). Health service systems are provided for their people by the government. Health policies set the vision on the responsibility in services and organizing health services. Thus, people will have better health conditions. The health services must meet people's needs and expectations. In addition, service and care with quality and efficiency must be equally and fairly distributed (WHO, 2000a: 119).

Common problems for health service management are:

1. Healthcare outreach setting

In Thailand, healthcare settings under the Ministry of Public Health are categorized into three levels: 1). Primary care with 9,592 primary health centers in

each city (Tambol); 2). Secondary care with 708 community hospitals in each district (Amphoe) with capacities of ten-100 beds and; 3). Tertiary care with 92 central hospitals and provincial hospitals offering services from general care to special treatment. Besides, there are five university (research) hospitals under the Ministry of University Affairs. In Bangkok, there are seven general hospitals and 61 health service centers under the management of Bangkok Metropolitan Administration. There are also about 290 private hospitals around Thailand (Ministry of Public Health, 1998: 27-28).

At healthcare centers, nurses and public health workers are able to provide primary treatment and relief of symptoms of the illness, but they are not able to diagnose or screen any symptoms related to AIDS or opportunistic symptoms. Community hospitals are able to perform treatment in accordance with the symptoms, but they are not able to diagnose any complicated illnesses. This leads many HIV/AIDS patients to avoid seeking treatment from health service settings in their community as the services offered do not meet their needs or illnesses and they do not have confidence in the physicians. Most HIV/AIDS related treatment is offered at central hospitals or university hospitals. Services offered there include treatment with anti-retroviral medicines and medication to prevent infectious diseases or opportunistic infection. Most HIV/AIDS patients seek treatment at these settings. In fact, these patients take up to 40% of the occupancy at these health settings (UNAIDS Report, 2000: 2). This causes delays and low quality of treatment.

2. Inadequate financing and human resources

It was found that finances and human resources allocation for heavily affected area in the north of Thailand is not sufficient. There is no decentralization and no

effective distribution of resources to local areas. Some community hospitals which serve as health networks could run out of medicine, and patients have to return to central hospitals to get treatment. The central hospitals suffer from a swollen number of patients. Central hospitals also have human resource and medicine problems because of the limited budget granted. Treatment is not standardized, and healthcare personnel do not have firm knowledge in AIDS treatment. Many care providers feel that AIDS treatment is too complicated for them to perform. This leads to the lack of confidence in treating patients (Department of Communicable Disease Control, The Division of AIDS, 1997: 24).

The role of health services is to provide primary treatment. Most nurses are only technical nurses or public health workers who do not have a university degree education. They are not able to perform treatment on complicated symptoms as appear in HIV/AIDS patients. Most of the treatment offered are medicine to relieve the symptoms such as painkillers (Senarat, V. 1999: 312). Distribution of support at the community level is also limited because most of the personnel have a degree lower than a bachelor's degree and lack medical practice in primary treatment and referral (Boontong, T., Ed, 1999: 66).

The treatment offered by community voluntary groups or NGOs is at limited level as the patients are referred from government health settings. The services aim at providing mental, social, and financial support. They are not able to offer diagnosis or treatment. This leads to an interruption of treatment as the organizations themselves also suffer limited human resources and finances (Department of Communicable Disease Control, The Division of AIDS, 1999b: 20).

3. High cost of care

About 60% of management cost come from the government budget, and 40% come from the patients or social welfare (covering about 45 million people). About 15 million people (25 %) are not covered by medical financing scheme and have to pay their own medical bills. Most people end up paying 74% of their medical costs. This is higher than government cost compared with many countries in the same region (Nitayaramphong, S. 1999: 34).

The majority of HIV/AIDS patients are from working group (20-39 years), women, children, and low-income people. Some patients are out of work and have to depend on their relatives and families. HIV/AIDS can cause a reduction of family income by 71%. Many patients suffer from their daily expenses. Some must quit their job, their children must quit school, some must move from their house, and some have to seek assistance from the community (Kongsin, et al., 2000: D.379). HIV/AIDS directly affects a patient's financial status, social situation, and health status. Some who have social welfare benefits are refused by their hospitals, while others are not satisfied with the service they receive and turn to private hospitals, which means high medical bills (Wattradul, D. 1994: 62). Moreover, the government does not offer any social welfare policy to cover the cost of medication. In addition, the cost of medication for anti-retroviral therapy and antibiotics is expensive, and it can be as high as \$4.40, which is higher than the minimum wage. The welfare available does not cover some groups of medicine either. Therefore, only 1% of HIV/AIDS patients have complete access to services (Reuters, 2000: 1). Patients with all healthcare schemes from the Ministry of Public Health and social security insurance must pay for some expensive medicines and anti-retroviral drugs which are not covered in the program.

They also cannot obtain other healthcare coverage from hospitals outside their province because some health welfare is limited only in their local areas (Senarat, V. 1999: 312). This clearly shows that HIV/AIDS patients with low income can rarely access the health service.

4. No continuity and no holistic care

The evaluation of implementation of the National AIDS Prevention and Alleviation Plan (The Division of AIDS, Department of Communicable Disease Control, 1998; 1999) indicates health services for HIV/AIDS patients as follows:

4.1 Provider-oriented care

Health service for HIV/AIDS patients at all levels is a provider-oriented method with passive practice and treatment to relieve the apparent symptoms. The care lacks systematic continuity. There is no effective evaluation and/or follow-up on the treatment performed (Kattipong, P., et al., 1999: 5). In some communities, HIV/AIDS patients receive few counseling or home visits, while others receive financial aid from social workers but do not receive information on self-care (Senarat, V. 1999: 312).

4.2 Inadequate community participation

Care management in families and communities is conducted by healthcare providers who are government officials. The community is not ready to accept the patients. HIV/AIDS patient groups are not clearly set up. Patients and their families may not want to expose themselves as they fear rejection and they would not let staff or volunteers visit them at home. Moreover, City Administrative Organizations are not concerned about the AIDS problems. Many HIV/AIDS patients are cared for by their family, but the family is not confident in the care they are providing as they are

concerned that they may be infected themselves. Also, most families do not know how to take care of seriously ill patients (Department of Communicable Disease Control, The Division of AIDS, 1999: 7; Senarat, V. 1999: 312).

4.3 Inadequate service for AIDS patients

Even though the government makes an effort to improve the quality of the services by establishing healthcare centers, these centers are founded only in government hospitals. Patients must travel to receive care at the service settings. In other words, they have problems with traveling expenses as these centers are not widely set up. Some HIV/AIDS patients refuse to receive services from their community health settings as they are concerned that people will know about their health status and may reject them (Department of Communicable Disease Control, The Division of AIDS, 1998: 4-23). There are no primary consultative systems in the community. The volunteer groups or city organizations are not able to offer appropriate counseling for HIV/AIDS patients (Senarat, V. 1999: 312).

4.4 Healthcare providers' discrimination

It was found that many HIV/AIDS patients could not get complete service from government health services settings because some personnel had negative attitudes toward the patients. Some patients ended up seeking service from other health service settings available such as private hospitals, temples, illegal clinics, or herbal treatment (Working Committee on Treatment and Committee of Non Government Organization against AIDS, 1997: 1-2; Saengchat, B. 1997: d; Songsaeng, S., 1998: d; Phrompakdi, S. 1998). Patients end up paying more money on traveling cost and treatment cost. Definitely, financial difficulty is inevitable.

There is also a lack of public facilities. This affects continuity of treatment or access to facilities. This causes problems for prevention and control of AIDS symptoms especially the opportunistic symptoms. Patients are delayed in their treatment, their health deteriorates, symptom prediction is not good, and disability and the death rate is high. Therefore, the government ends up spending more on chronic illness treatment than primary prevention (Tremble, et al., 1996: 510; Menke, et al., 1997: 295; Mahon, et al., 1993: 123).

Policies must give guidelines in managing health services. The services should promote health status, meet the HIV/AIDS patient's expectation, and be widely available to everyone. The healthcare service should be accessible, effective, and equal and it should offer financial protection for disadvantaged groups like HIV/AIDS patients. The government should reform its health service system to create a balance between services and limited resources. In order to do so, information from patients as service receivers is required so as to make then health services offered cost effective with universal coverage and minimum cost.

Nursing knowledge: Access to healthcare service

The development of nursing knowledge is often aimed at the solution for patients' behavioral/medical aspects, whereas the social, economic, and political aspects which play an important role in people's health status are overlooked. The American Nurses Association (American Nurses Association, 1991; cited by Joel, 1992: 222) suggested that health policies that emphasize the access, quality, cost, and implementation should involve the country's economy and political situation. There are some research studies on access to health services with differences in cultures,

racess, society, and political systems (Leenerts, 1998; Steven, 1993; Andrson, 1985; Martin & Henry, 1989; cited by Steven, 1992; 192). These research studies aim to study the unequal access to health services and problems of access to health services that are related to social, economic, cultural, and political conditions. There are factors that support better access to health services with nurses as advocates, and there must be social and financial support in order to achieve the goal (Steven, 1992: 194).

Access to health services for HIV/AIDS patients

There are about 110 research studies (through AIDS LINE and MEDLINE Database) investigating access to health services for HIV/AIDS patients. Most of these research studies were cooperated research from multidisciplinary professions. The access to anti-retroviral medicines and influential factors on the access to health services were the main studies of these research studies (Anderson, 2000: 389-416; Abramowitz & Obten, 1998:8-9 ; Schilder, et al., 1998: 607). Some emphasized the need for health services or social welfare that encouraged access to health services (Tremble, et al., 1998:510), while others studied the access to healthcare and obstacles to healthcare for HIV/AIDS patients under a health plan (Medicaid) as a follow-up on managed care system (Rapkin, et al., 1998: 833-834).

There were 24 nursing research studies (selected through AIDS-LINE and Ovid-CINAHL) related to access to heath services for HIV/AIDS patients. These studies were conducted among homosexuals, women, homeless people, drug abusers, and ethnic groups found in the U.S. and Canada. For instance, Schilder and colleagues (1998a: 607; b: 1055-1056, c: 601) found that homosexuals, transgendered, and bisexual males with drug problems did not receive complete treatment. Care providers

did not have a positive attitude toward this group of patients. Their mental problems were ignored. Information on prevention of opportunistic infections was not given as the care providers thought that this group of patients was incapable of taking care of themselves. Many of the care providers lacked skill and had no special knowledge in treatment of drug addicts, anti-retroviral management, and female hormone for transgenders. Healthcare services were not effectively coordinated in referral care leading to discriminating care. All these caused many patients to avoid treatment, which led to severe conditions of the patients.

As for research on access for female patients, it was found that women did not gain equal access to health services when compared to male patients at the same stage. The screening for treatment was based on age and race (Patricia & Farrell, 1998: 407). Most HIV/AIDS female patients were not diagnosed, did not have access to health information, and lacked support on treatment and social welfare (Donnan, 1991: 461). Research on female minority groups also indicated that there was unequal access to public health service and that the service was not of quality. There were no health promotions or illness prevention services. The care providers showed no respect for the patients and patients began to be worried and avoid the treatment. These studies indicated that community health services must be reformed to provide services with quality and efficiency and should meet people's needs. The government should promote health services and set them as the first priority for people especially minorities (Stevens, 1993: 39-56).

In addition, some research studies indicated problems and obstacles in accessing health services for poor and wandering group of HIV/AIDS patients with tuberculosis (TB) in New York. The finding indicated that patients were not given

appointments for continual treatment. Health service settings did not have sufficient time and/or medicine. Health insurance did not cover or facilitate patients with TB to access effective treatment. Patients urgently needed food, housing, and medical service. Care workers often discriminated and were prejudiced against homosexual and bisexual groups. Moreover, the service given was not of quality. Their partners did not get involved in making decision. They were not given information on safe sex. Finally, care providers did not have a positive attitude towards patients (Tremble, et al, 1998: 510). All of these conditions should be taken into consideration as they are important factors in determining access to health services (Rapkin, 1998: 833-834).

Some studies also indicated that access to information, skill, decision making, and social support increases the quality of a patient's life. If patients participated more in self-care, the time spent at hospitals was reduced. The expense of care was also low (Boberg, et al., 1996: 57). This knowledge from each country shows that implementation and reform of policies for better access for HIV/AIDS patients has been carried out continuously. In addition, it would serve as guidelines for the nursing profession that will promote access to a comprehensive healthcare system for HIV/AIDS patients (Eversley, 1995: 22-24).

Experience of accessing health service for HIV/AIDS patients in Thailand

A search in Mulinet, Library of Mahidol University, indicated that there is no research or study of HIV/AIDS regarding the access to health services in Thailand. Most, if not all, research seemed to study the health behavior of HIV/AIDS patients. These behaviors could be considered as self care. The patients seek alternative health services such as temples, folk or local doctors, and illegal doctors. The care seeking

included alternative or folk care related to the belief and culture of HIV/AIDS patients such as using blessed water or spiritual mediums (Songsaeng, S., 1998: d; Phrompakdi, S., 1998: 6; Saengchat, B., 1997: d).

As for the knowledge on providing care for HIV/AIDS patients, most were aimed at theoretical tests for nursing knowledge such as Orem's Self-Care Theory. (Orem, 1991; 1998), which studies the basic conditioning factors such as gender, age, educational level, and income and their relationship to self-care. Some research indicated obstacles in patients' self-care. For example, care providers did not have a positive attitude towards care receivers. There was no confidentiality on information and a lack of financial support such as healthcare card and social security card (Wattradul, D., 1994: 63). Some patients were refused admission, and there was discrimination from health providers. In addition, their families had to look for hospitals for the patients (Chunhapran, P., 1996: 34). All of the research confirmed that patients must be able to take care of themselves as health service systems do not facilitate them in their goals and needs.

Moreover, the study in the north of Thailand demonstrated that the health service system available did not meet the HIV/AIDS patients' needs, especially at the community level. The budget for AIDS prevention and alleviation was allocated in the north of Thailand. However, the inadequate budget and coordination with other offices, in particular unfair budget management and lack of project evaluation, caused many patients to turn to any available services. For example, every HIV/AIDS patient had experience in seeking care from various healthcare settings ranging from private hospitals, governmental hospitals, clinics, to illegal doctors. These health-seeking behaviors caused patients to suffer from understand or ineffective care and services

and spend a lot of money on transportation. Often, this added a great deal to cost of treatment that did not meet the standard and quality of care (Phrompakdee, S., 1996: 24).

However, there have been some studies of healthcare needs of HIV/AIDS patients. For instance, there was one study of healthcare needs in people living with HIV/AIDS who utilized healthcare services in tertiary healthcare settings. The result of the research indicated that patients with HIV/AIDS have many health problems, both physical and psycho-social, thus leading to a poor quality of life. Most of them have a high level of healthcare needs in psycho-socio-economic, health behavior, social support, and health management. In addition, healthcare needs of the patients are correlated to changing of family role, severity of illness, physical changes and physical ability (Wiriyasombat, R., 1997: 98-102). Another study of the healthcare needs of HIV/AIDS patients in the community level showed that factors significantly associated with their needs are sex, past illness, daily living activity, and available social support network (Powthongrit, K., 1998: 82-88). These studies implied that healthcare systems should be provided to respond to the needs of patients with HIV/AIDS and offer services that can improve the patients' physical-psycho-social health in order to promote their family role and involvement with social support in community.

The study of the Office of Policy and Higher Education Plan (1999: 4-5) showed that most HIV/AIDS patients did not have access to services provided by the government. Patients came for treatment at the beginning but discontinued it after a time. This might be because the services provided were not universally accessible or of quality. In all the literature concerning healthcare systems reviewed, the findings

showed that there was no appropriate healthcare system for patients with HIV/AIDS. The information from healthcare providers in the past and present such as that concerning successful and failed healthcare services and policy implementations in Thailand and other countries can be solid data of policy development.

The researcher believes that the health service pattern in Thailand for HIV/AIDS patients aiming at providing access to the services is not clear-cut. There is a lack of basic knowledge from patients with HIV/AIDS who are on the consumer side. Thus, the study of experiences of HIV/AIDS persons in accessing healthcare systems will be the important data for the improvement of healthcare services. In order to establish a healthcare policy that meets mutual goals of both healthcare providers and patients with HIV/AIDS, thorough understanding of their knowledge is needed. Therefore, it is anticipated that a bottom-up policy generated from the grassroots' side will lead to a better health policy or reform for HIV/AIDS patients and other disadvantaged groups in the future.

CHAPTER III

METHODOLOGY

This chapter focuses on depiction of the research design and methods applied to conduct this study. A description of the research design, source of data, setting, data collection, data analysis, trustworthiness, as well as protection of human subjects, are included in this chapter.

Research Design

Herbermas's theory of communicative action basically rests a distinction between two concepts of rationality that construct knowledge to guide action (Habermas, 1984:8-22, 168-185). First, cognitive-instrumental rationality conducts action that aims at the successful realization of privately defined goals. These action types are either instrumental, when they are directed at effective interventions in a stage of affairs in the society such as through persons with HIV/AIDS, or strategic, when they guide attempts to successfully influence the decisions of the domination such as policy makers. Second, communicative rationality underlines action that aimed at mutual understanding, conceive as a process of reaching agreement between speaking subjects to coincide their interpretation of the society. In addition, it is only through language, under conditions of rational argumentation, that persons in society can coordinate their actions in terms of an orientation to mutual understanding. Thus, knowledge constructed by human communication throughout language is the most fundamental aspect of reality.

The qualitative methodology of narrative interpretation was used as the research design in this project. Narrative interpretative is well suited to this study because it correlates to Habermas' communicative action theory valuing reality of inter-subjectivity perspective (Habermas, 1971:309, Anderson, 2000: 3-4; Kellner, 2001: 2-3). Narratives provide the social texture of recreating the situation, providing the researcher the opportunity to demonstrate the limitation of prior events or actions and the orientation of the succession. Narratives provide detail to data, allowing the researcher to see interpretations of the oppressions that can make their inner nature transparent to others and provide suggestions to new instruments of discovery (Habermas, 1972: 144; Calhoun, 1995; cited by Curran & Takata, 1999: 4).

Thus, this methodology is used to synthesize the more equity healthcare policy, making an effort to integrate the interconnection between healthcare power and disadvantaged persons with HIV/AIDS who are oppressed. Narrative is appropriate and useful for understanding what persons with HIV/AIDS discourse about experience in utilizing healthcare services through their stories. Furthermore, it is used to examine disadvantaged inequality group and critique health policy power and healthcare systems that affect persons with HIV/AIDS in utilizing health services leading to having health and social problems (Riessman, 1993: 5; Sandelowski, 1991: 161-162). The ultimate goal of this methodology is to synthesize the guideline of healthcare policy by integrating the knowledge of both dominant and oppressive sides conducting to determine equitable and justifiable healthcare policy for persons with HIV/AIDS.

In this study, the systemic forms of narrative analysis comprised two terms of inquiry. Top-down represents dominant investigation in terms of documents. In

addition, bottom-up refers to persons with HIV/AIDS who have experiences in accessing healthcare systems (Manning & Cullum-Swan, 1994: 464).

Top-down narrative of the documents or text represents the history influencing systems and structures of healthcare by spoken and/or written discourse and dominant action. Languages in documents mediate social reality in the authority side. Thus, to investigate the policy of healthcare systems related to HIV/AIDS, they can be interpreted and understood as text (Hiraki, 1992: 2). The interpretation of text creates understanding of the sources of domination and deformed communication within the legend. A systematic critique of the assertions that constitute a policy is needed to reveal the power relation entrenched in communication and in the power character of tradition (Habermas, 1973, 1976; cited by Hiraki, 1992: 2). In addition, to fully understand social action, a critique should include the story of the oppressed side.

Bottom-up narratives derive context of subordinate or HIV/AIDS group to produce an infrastructure that justifies the story's meaning. Personal narratives are testimonies that elaborate personalized life experiences and survival. Testimonies are stories that specifically link one's history of agony and hope with those previously or currently in similar situations. The story of individual's behavior in accessing healthcare is told and reflected by his or her own perspective. The people living with HIV/AIDS tell stories to describe and explain what struggle and experiences of healthcare have happened to them. The healthcare experiences are associated with the stories of unequal, unsatisfied experiences, and repressive retribution by dominant groups such as healthcare providers and policy makers (Hall, 1999: 99-100). This study will link the reality of persons with HIV/AIDS experiences by understanding

their emic view based on the context of value, culture, socioeconomy and environment that affect them as well as fostering hope and connectedness among disadvantaged groups like persons with HIV/AIDS (Denzin & Lincoln, 1994: 12; Hall, 1999: 100).

According to Habermas' discourse theory, every communicative act claims validity in terms of truth, rightness, and honesty (Habermas, 1984: 126-127; Anderson, 2000: 3). Therefore, both top-down and bottom-up approaches are integrated with mutual understanding and coordinating, leading to formulate discursive justification. In addition, the informed action or policy will be generated by synthesizing from those who are under pressure and authority toward achieving agreement in terms of equity and justness. Thus, Critical theory, dialectical methodology (Kellner, 2001: 3), will open the space for thought and action through the synthesis of recommendations for a 'model' healthcare policy, in order to improve and promote persons with HIV/AIDS' health and quality of life.

This critical narrative study was designed to explore persons with HIV/AIDS's healthcare experiences. Throughout their healthcare stories, the meanings of experiences in access healthcare for persons with HIV/AIDS in the contexts of their lives were evolved. Participants with HIV/AIDS were encouraged to recite their healthcare experiences including: 1) negative experiences that hindered them in accessing healthcare services, 2) positive experiences that facilitated their access to healthcare services, and 3) healthcare needs and expectation of persons with HIV/AIDS. Together with participants, the investigator developed the recommendations of care and services for persons with HIV/AIDS and addressed the issue of interest and drew conclusions about how healthcare might be improved.

Research Assumptions

This study was undergirded by the following principle assumptions:

1) Persons are self-reflective, contemplative beings in particular historical, cultural, socioeconomic and political contexts. Healthcare refers to individuals' healthcare, healthy life style, family and community healthcare including society healthcare, which is affected by their environmental contexts; 2) Their perceptions of reality are influenced by the cultural, socioeconomic, political, physical and psychological contexts of perceivers, hence there are multiple realities in terms of contexts in which persons find themselves; 3) Persons have awareness of reality and are agents of knowledge; 4) The researcher is viewable, historical individuals with compound interests; and 5) The researcher has an assignment and believe in the value of the phenomena and research and theory development that are one distinguished for their knowledge, experiences, wisdom, sound judgment, and political activities.

Setting and Source of Data

Setting: Diversity of settings in different parts of Thailand

The criterion of setting selection was based on the epidemic and morbidity of the HIV/AIDS population. The availability of healthcare settings that provide health services for persons with HIV/AIDS in different settings included primary healthcare, secondary healthcare, and tertiary care. Another indicator of setting option depended upon the diversity of people living with HIV/AIDS who lived there. The diversity included culture, socioeconomy, and countrywide ethnicity. As a result, the five settings used for conducting research are explained by geographic bases as follows:

1. Bangkok: Two university hospitals, one general hospital, and specific clinics

Bangkok, the capital, is the representative of a big city in the central part, with enriched sources and facilities especially healthcare services for persons with HIV/AIDS. There are several university hospitals, which provide up-to-date and effective treatment affordable for HIV/AIDS patients. The university hospitals and general hospitals are an example of full medical treatment and care. Furthermore, there are many HIV/AIDS clubs and support groups for patients with HIV/AIDS. However, there are some limited sources such as no admission of HIV/AIDS patients for further treatment and no healthcare scheme for mobile workers and those with low income.

The researcher could access two university hospitals where there are several experts, specific clinics and medical clinic to provide treatment and care for persons with HIV/AIDS. The healthcare services in Bangkok could explain the crowd of persons with HIV/AIDS who need specific care and face the inequity in access to quality treatment and care. The researcher could meet and invite a few patients with HIV/AIDS at out-patients department to participate in the project. The rush environment of limited time while patients needed high demand of services resulted in the patients' unwillingness to join the interviews. Thus, the researcher chose to meet meningitis participants who came to receive anti-fungal therapy at Day Care service. In addition, due to the limitation of beds for admitting patients with HIV/AIDS, the researcher could meet few patients at in-patient departments. Besides, there are some international NGOs that provide anti-retroviral therapy via the project joined with a university hospital. Thus, the researcher could also meet a few patients who had

access to treatment and care at specific clinic and non-specific clinic. In addition, HIV/AIDS club at healthcare setting was the place for collecting data.

From literature review, there are some persons with HIV/AIDS who are AIDS infected by intravenous drug use (IVDUs). The researcher tried to find the sample at the specific clinic for IVDUs. However, there were some troubles to access the sample at drug addict clinics because most clients at clinics did not have voluntary blood testing and were informed of the blood test. Thus, only few persons with HIV/AIDS at drug addict clinic were included in this study.

2. Phayao: A general hospital, a community hospital, and health centers

Phayao Province located in the north is the first rank of HIV/AIDS epidemic in Thailand. The number of HIV-related illness is 169.4 per 100,000 (Division of Epidemiology, 2000: 1). In addition, there are general hospitals and community hospitals where persons with HIV/AIDS go to receive treatment and care. Phayao represented the situation of high healthcare demand and of limited resources. The researcher could access a variety of healthcare services in Phayao such as primary healthcare, secondary care, and tertiary care.

Due to the type of patients with HIV/AIDS and the limitation of service in the out-patient department, the researcher did not have opportunity to meet and interview participants. The investigator could meet and interview several patients at the in-patient department in a provincial hospital. There were also a few experts and some anti-retroviral therapy project at tertiary health settings. In addition, the researcher met a few participants at a health center and a community hospital in Phayao. The researcher could access a group of volunteers with HIV/AIDS who joined the home visit program with the NGOs at a health center in the district far from the urban area in

Phayao. Furthermore, a community hospital and day care service were also included as the setting for the study.

3. Phuket: A general hospital, Day Care service, and HIV club

Phuket Province, a city for tourism industry, is located in the south of Thailand. Phuket is the fifth rank of high HIV/AIDS incidence. The proportion of HIV/AIDS population is 103.4 per 100,000 (Division of Epidemiology, 2000:1). Phuket depicts divergent population from a variety of cultures in the south. In addition, it is the place for mobile laborers from the provinces around Phuket and other parts of Thailand. Therefore, the experiences of local people and mobile workers in access to healthcare settings in Phuket can explain healthcare services in the southern part of Thailand.

The healthcare systems in Phuket could describe the abilities of access to care for people living with HIV/AIDS in high economic growth in an urban area. Thus, there are specific treatment and investigation for HIV/AIDS at private hospitals, while a government hospital cannot provide specific treatment and care. The researcher could meet few mobile workers and local people with HIV/AIDS at in-patient units. In addition, the researcher met the majority groups of persons with HIV/AIDS who utilized Day care services in a provincial hospital. Several participants of the HIV club were willing to join the project. Thus, the setting to obtain the project was mostly specific in the HIV/AIDS club in their community because the problems and disclosure of AIDS situation are still sensitive in Phuket.

4. Surin: A general hospital, a community hospital, and Day Care

Surin Province was chosen as the setting of the northeast because it has the lowest incidence of HIV/AIDS in Thailand. Although the incidence of HIV/AIDS population is not high in Surin, it delineates healthcare setting of low incidence HIV/AIDS and multi-cultures of people influenced by Laos and Cambodia. The study of healthcare system especially for HIV/AIDS can therefore represent a low profile situation among other settings in Thailand.

The researcher could access to a variety of healthcare settings such as a general hospital and a community hospital. The general hospital is a tertiary care where there is a specific clinic for anti-retroviral therapy project joined with an international NGOs. Thus, a lot of persons with HIV/AIDS from other nearby provinces in the northeast come to use healthcare leading to the crowd of patients at the out-patient unit. At a healthcare facility in Surin, the researcher could approach the participants at both out-patient unit and in-patient unit. In addition, the researcher gained access to one community hospital which is near the border of Cambodia. The healthcare setting in the community could describe inadequate resources and the difficult access of people in the rural area far way from the center of the city. The limitation of the distributions of healthcare services in the community hospital and provincial hospital could reflect the struggle experiences in accessing healthcare in the northeast of Thailand.

5. Rayong: A general hospital and HIV club

Rayong, the fourth rank of high HIV/ AIDS incidence was selected to represent the setting in the east of Thailand. There are a lot of local workers and mobile workers at industrial areas. The incidence of HIV/AIDS population is 116.9

per 100,000 (Division of Epidemiology, 2000: 1). This setting represents high incidence of HIV/AIDS among mobile workers and local population in the east. This healthcare setting depicts special services related to people's health problems.

The researcher could access one government hospital in Rayong. Although Rayong is one of the rapidly growing economic areas in Thailand, the tertiary healthcare setting lacks experts and special treatment of HIV/AIDS. There are no specific clinics for anti-retroviral therapy project and special laboratory for investigations. Thus, persons with HIV/AIDS who do not have healthcare coverage cannot access anti-retroviral therapy at the provincial hospital. A lot of participants who need special treatment try to access the center government hospital in other provinces. The researcher could meet participants at the out-patient unit and in-patient unit. The healthcare services in Rayong could describe the limitation of resources where patients' high demand of cares are not met. The researcher could interview most of the participants at the out-patient department and the HIV club at a provincial hospital.

Sources of data

This project aimed to criticize both top-down and bottom-up narratives. Top-down narrative refers to the etic view that generates better understanding of the dominant side that affects and involves health and well-being of the disadvantaged groups. Bottom-up narrative refers to the emic view that creates real stories from the narrator's point of view in societies (Hodder, 1994: 393-395). Consequently, sources of data in this study consisted of two categories; document data and participant data that are described as follows:

1. Document Data

Documents are unobtrusive measures that the investigator do not intrude in the research context. The document data were prepared for certifying some formal records of the proceeding of a society, or healthcare systems. They require more contextual interpretation. The interpretation of text makes the potential value reflection on symbolic meaning contributing to understand experiences of persons with HIV/AIDS. In addition, documents involve system technology and record a full state system power. Document as a text is reread in different contexts. It gives new meaning or contrary and socially embedded meaning regarding the context of healthcare systems. Consequently, the document interpretation will monitor and justify what health policy says and what it has not been conducted. The document data from Thailand and other countries were prepared as the database in the literature review.

The various documents play a vital role in delivering information about the national plan for HIV/AIDS care, national and organizational structures and context, as well as budgets and evaluation of the policies. The national contexts that are related to the AIDS situation are socioeconomic, political, and health systems. The unobtrusive method acknowledges that the investigator is to examine public message at this situation which can be applied to be the data in a study (Correa, 2000: 5).

Document data are varieties of publishing matters. For instance, text, journals, electronic matters, journals, and fact sheets in Thailand and other countries are needed. The criteria for selecting document data in the present study included:

1.1. Quantitative data: the measurable data e.g. number of HIV/AIDS populations, population income, gross domestic product (GDP), and the budgets, etc.

1.2. Qualitative data : all the information regarding health policies such as national plans for AIDS care, regulations and ACT, and healthcare system management.

1.3. The publishing matters: the information distributed from the government, non-government organizations (NGOs), private sectors, and any institutions.

1.4. Two versions of the document : there were two versions of Thai and English documents selected for analysis. The publication date was within five years.

Document data collection

Numerous documents related to the national plan, health policies and strategies for HIV/AIDS care as well as healthcare system were collected to obtain data by:

1.1.Searching: various web sites on the Internet were searched. In particular, WHO, UNAIDS, UNDP and Ministry of health of many countries especially the U.S.A., United Kingdom, Australia, South Africa, Canada, and Asian countries were easily accessed. In addition, the letters requiring data concerning healthcare policy and services related to HIV/AIDS were sent via e-mail to the institution that could offer the documents.

1.2. Collecting: information of healthcare policy related to HIV/AIDS care in Thailand was gathered by searching the existing documents and published information on healthcare policies for persons with HIV/AIDS in Thailand and other countries. These documents were obtained from the division of AIDS, Ministry of

Public health, NGOs and national organizations such as UNAIDS and WHO located in Thailand.

1.3. Confirming: the knowledge of accessing the healthcare system of HIV/AIDS persons in Thailand and other countries were confirmed. Information was also searched for and confirmed from universities and institutions in Bangkok, as well as interlibrary networks including databases such as AIDS LINE, PUB-NET, MED LINE, and various Internet web sites.

Various document data were obtained from a lot of sources; in particular, database from the Internet, libraries and institutions. Document data were analyzed by using document analysis (Hiraki, 1992: 4-8). In addition, the findings from the literature review were used as a guideline to construct semi-structured interview and to justify with inter-subjectivity while interviewing participants. Document data related to healthcare systems of Thailand and other countries such as the U.S.A., Africa, and others offered a lot of information in terms of healthcare structures, society, economy, and politics that influenced environments, health, and wellness of people living with HIV/AIDS. The investigator could gain better understanding in the context of etic views regarding dominant sides.

2. Participant data

Participant data were important main data that the investigator explored. There were two types of participant data in this study. First, obtrusive interview represented data from the participants' story telling. These data were gathered from HIV/AIDS participants in Thailand. Second, obtrusive documents were produced from participants' personal information and history of illness in healthcare settings.

Maximizing Diversity of participant groups

In order to study a large population group of persons with HIV/AIDS in Thailand, the investigator had to derive the sample from the significant representative groups. Therefore, purposive sampling was appropriate and was applied in this study.

Purposive Sampling

The selection of participants focused on 30 women and 20 men in five parts of Thailand based on the criteria on the diversity of geographic data, culture, socioeconomic factors, and their willingness to participate. Inclusion criteria were that participants were self-identified as HIV sero-positive and had received pre-and-post counseling from healthcare services. They were both males and females who were HIV infected or had HIV-related illness without cognitive impairment. Additional criteria for specifying the targeted population were adults aged over 15 years, with Thai nationality, and were able to communicate in and understand the Thai language. They had used or attempted to use a health facility in various health settings such as primary, secondary, and tertiary care at least once in the past three months.

Interview data that were obtained from purposive sampling could support diversity of participants in various settings. The researcher could access representatives of participants designated from the criteria. Most of the participants were in the adult age groups ranging from 22 to 54 years of age. However, the researcher could not find the participants who were younger adults whose age were from 15 to 20 years. This younger adult group is the risk group of HIV infection, but they rarely utilize health services because they still have asymptomatic AIDS. Thus, the young adults were missing in this study. All of the participants who agreed to

participate in this study were willing to tell their stories of experiences in healthcare services.

Theoretical Sampling

Another method of the selection of interview participants was called theoretical sampling (Strauss & Corbin, 1998: 202-203; Strauss, 1990: 274-277). This theoretical sampling was used to cumulate each sample building to add to previous data collection and analysis. After previous analysis of the data collection, the researcher found the beginning of a speculation. Then the researcher chose each specific group of participants in a specific healthcare setting and health service provision to make comparisons of the story they told with the data which had already been assembled and analyzed. The categories of findings were analyzed in terms of elaborating, conformity, and saturating.

In this research, the immediate apprehensions of the ongoing analysis suggested that the quality and cost of healthcare were vitally important to persons with HIV/AIDS. The quality and cost of care became the significant indicators of socioeconomic events that influenced persons with HIV/AIDS as they attempted to access healthcare systems. The data collection from one healthcare setting revealed persons with HIV/AIDS, especially HIV volunteers, who received quality of care and treatment from an anti-retroviral therapy project and were still healthy. Thus, theoretical sampling was used in order to compare the analysis data by collecting data from other persons with HIV/AIDS who could not receive anti-retroviral therapy. Thirty-six participants (76%) with HIV/AIDS who did not receive anti-retroviral therapy in various healthcare settings could support the complete data analysis.

Furthermore, some persons with HIV/AIDS who were government employees had health welfare for state employees and anti-retroviral therapy coverage. Hence, theoretical sampling was used to compare them with the others who could not receive anti-retroviral therapy due to the limitation of health financing schemes. Participants who did not have health welfare and healthcare coverage of the treatment of AIDS were specific groups for collecting data. To maximize diversity, participants in five different parts of Thailand in each healthcare setting and with different access in healthcare provisions and health financing scheme were included in this study.

As the cost of AIDS treatment and care had impact on persons with HIV/AIDS in access to health service, socioeconomic diversity was used in theoretical sampling. Thus, participants with various economic statuses were recruited in this study. The incomes of participants ranged from Baht 500 to Baht 25,000. However, most of the participants who felt free to tell their story were unemployed and had low income, so they had a lot of trouble in utilizing healthcare services. Although the high-income participants and employees were not the majority group in this study, they could express the difficulties and inequity in access to health welfare and quality of care. Therefore, the researcher could find and develop the knowledge of this study regarding the importance of the cost of care and health-financing schemes in distinguishing healthcare experience.

The persons with HIV/AIDS 's health status could represent different experiences in the healthcare system. Thus, theoretical sampling was used to specify persons with HIV/AIDS who had good health status and compared them with those who had poor health status. In this study, the comparative groups related to health status were analyzed. The researcher could find the different and quality healthcare

services which either disrupted or promoted persons with HIV/AIDS in access to healthcare system.

Another obtrusive document used in the project was the personal information data comprised information related to personal background and socioeconomic factors, cultural factors, and illness-related factors of participants. Biographic and cultural data included age, marital status, religion, educational level, status or role in the family and number of family members in the household. Moreover, socioeconomic data included type of healthcare service payment, occupation, and income per month. Finally, illness-related factors included onset and duration of HIV infection, history of illness and treatment, recent medication and treatment, and hospitalization experiences. Personal information sheet can be found in Appendix A.

Data Collection

Participants' data were collected by means of participant interviews and participants' documents. The procedure of data collection can be described as follows:

Participants' data collection

Individual Interview

Interviewed data were collected at various healthcare settings, and participants' homes in the selected cities across Thailand. The places where investigator met and interviewed participants were flexible and suitable for the participants' convenience and comfort. For instance, the private rooms at HIV clubs, outpatient departments, and wards facilitated the researcher to conduct each participant's interview. Thus, participants did not have any worry, and they knew that

the data collection was kept confidential during the interview process. Some participants, who were home visited by healthcare providers, felt comfortable and allowed the researcher to interview them at their residences. Prior to the initiation of the interview process, the investigator used the strategy to meet participants and conduct interview as follows:

The formal access to healthcare settings

In order to protect human right and to ensure ethical consideration, formal letters from Mahidol University were used to communicate between the investigator and ethical committees at healthcare settings. As research involving human subjects, especially those with HIV/AIDS at healthcare settings, was a sensitive issue, the researcher had to explain the purpose and benefits of the research. The director of healthcare settings and the committees of ethical consideration had to agree with conducting the research. The process of requiring ethical consideration permission from a healthcare setting took about three to four months. After receiving the permission from executive administrators, the investigator received good supports and coordination from physicians and staff nurses who worked at healthcare settings. The example of documentary proof of ethical clearance on human rights related to research involving human subjects from healthcare settings is shown in Appendix B.

Introduction in access to participants

Professional nurses were good facilitators in conducting purposive participant selection. They could coordinate and describe the benefits of the study between the investigator and participants because HIV/AIDS participants trusted them. For this reason, nurses could assure and introduce HIV/AIDS participants who would like to disclose themselves voluntarily and participate in this project. Nurse facilitators

would first ask for permissions from participants, and then introduced the investigator to meet and interview them under the condition of informed consent. The researcher could interview this group of participants who were not the members of HIV/AIDS club. Most of them suffered from chronic illnesses and had been admitted in the hospital. Some of them received care and treatment at an out-patient department and at the emergency room. In addition, the researcher could interview participants at the participants' houses when doing home visit with staff nurses.

Nurse facilitators also introduced the researcher to meet the volunteers with HIV/AIDS who participated in the activities in support group at Day care service in hospitals. Some of the volunteers with HIV/AIDS did counseling and did home visits. Therefore, volunteers with HIV/AIDS who became the participants could facilitate the researcher in access to other participants when the researcher accompanied staff nurses to do home visits with them. The leaders or the managers of HIV/AIDS clubs in each healthcare setting were also good facilitators because they acted as both key informants and introducers. Thus, they could select HIV/AIDS members who would like to participate in this study.

Methods of data collection and specific interview technique

After interviewing the first participant who was a volunteer, the investigator could meet other participants who were recommended by previously interviewed participants. The methods of data collection were as follows:

- 1) Recruitment was conducted through purposive sampling using targeted chain referral by HIV/AIDS participants (Biernacki & Waldorf, 1981; cited by Stvens & Doerr, 1997: 524). HIV/AIDS participants who had been interviewed by the investigator were instrumental in successfully outreaching to other HIV/AIDS

participants. Most of them were the members of HIV/AIDS clubs who have utilized healthcare services at the same healthcare settings. Some of the participants were volunteers who participated in providing healthcare services with healthcare providers such as day care's counselors and home visits. As a result, they could recommend who could be participants in this study.

2) Every participant with HIV/AIDS was asked for permission from his or her friends or HIV members to recommend them to the researcher as would-be participants. Participants made appointment with the investigator to meet new participants. In addition, the investigator asked for permission and conducted informed consent before interviewing them. The method of sample selection could gain a lot of information from both participant mediators and recommended participants.

The data from each participant could be confirmed and triangulated between participants who were targeted chain referral at each health service in different parts of Thailand. In addition, the interview data triangulation from participants in the five parts could enhance reliability and validity and to increase comprehensiveness (Boyd, 1993: 458-459).

3) Participants who participated in the project had willingness to join the project because the researcher developed rapports and established trust to promote their willingness. In the interview process, the investigator used interview techniques to encourage participants to tell their story. The specific technique included empathetic listening and reflection used to encourage participants to have self-esteem and confidence. Therefore, they could tell and describe a story of their experiences deeply and precisely. Participants shared confidential details of their feelings,

comportment, and judgment concerning healthcare experiences. Furthermore, the investigator did not disrupt participants' patterns of association concerning their experiences in healthcare. Participants were allowed to use their own words instead of prescribing vocabularies. Moreover, the techniques of probe and reflection were used when experiential specificity or clarification was needed (Kerfoot & Sarosi, 1993; cited by Heiney, 1995: 899; Gergen, 1991; cited by Schwandt, 1994: 128; Patton, 1990: 326-333; Denzin, 1989: 102-110). The researcher used technique of listening rather than giving information resulting in participants' being respected as persons. They could have opportunities and advantages to voice and share what they needed which was important to them. As a result, the data could gain and increase validity (Denzin, 1989: 109, 113-114).

In-depth interviews of the participants were undertaken by the researcher under conditions of informed consent and were audiotaped. The time consumed during interviewing each participant was planned to be 60-90 minutes at healthcare settings. Most participants felt trusted and confidential during the interview process at their selected places such as their houses or HIV/AIDS clubs. Therefore, some interviews took more than two hours. The most convenient place and time to interview participants was the participants' residences. Thus, the researcher could interview and observe the participants' context and environments related to daily life and socioeconomic impacts.

Semi-structured interviews (shown in Appendix C) were conducted with initial questions and used as the guideline for interview. The researcher used interview guideline flexibly when interviewing each participant. The guideline of interview was useful when the researcher asked some participants who were hesitant

or could not express their experiences as they liked. The questions in the guideline could remind the interviewer of the topics that might be probed to develop the context bounding each healthcare circumstance the participants narrated. For instance, the question of experiences in healthcare, need and expectation of care and treatment, quality and quantity of healthcare provisions as well as the outcome of care were included. The questions could guide the researcher when asking for the details in general areas of healthcare for persons with HIV/AIDS.

Narrative process during interview

Trust and relationship between the researcher and participants

According to Habermas's critical theory and narratives interpretative methodology, communicative rationality was emphasized to establish mutual understanding, originated as a process of reaching agreement between participants and the researcher to harmonize their interpretation about experiences in healthcare systems (Habermas, 1984: 168-185). The researcher respected the good faith and validity of the participants' voices and rejected the notion that the researcher was an expert. The participants should have the same opportunity to express their attitudes, feelings, interests, and mentions. Therefore, the participants were honest or sincere in the relationship between the participants and the researcher (Habermas, 1972: 144). Most of the participants who were firstly interviewed in this study were willing to tell their stories about healthcare experiences because rapport and trust were established in all interviews. They were encouraged to speak in their own voice as they had never expressed their experiences or requested their healthcare needs to any persons before (Mishler, 1986: 119). Thus, they felt free to tell their experiences, both negative and positive, with healthcare systems. After they had known the purpose of this study,

they were avid to tell their stories and what happened to them in healthcare occurrences.

Emphatic listening and co-construction narrative

The process of emphatic listening encouraged participants to have the authority to tell their experiences in healthcare services. They began to have communication and self-reflection on how that happened and what it meant on the specialization of struggle of daily life and simultaneously the rational organization of everyday life and experience of healthcare culture that could bring about mutual understanding, rational consensus, future practices, and human emancipation (Harbermas, 1984: 36).

Both male and female participants could articulate in communicating their stories relating to their experiences in healthcare contexts. They described the factors that impeded and facilitated their access to healthcare services. They reflected on the quality and quantity of healthcare services that affected their health status and daily lives. They also mentioned the constrained socioeconomic, political, and social constraints that influenced healthcare access. They explained what they tried to obtain in healthcare services and required for their expectation and healthcare need that might improve healthcare services.

In the process of the co-construction, the participants especially women cried when telling their stories that were sensitive and were mentally moving. The researcher allowed them to delineate their suppressed feelings. They had opportunities to tell their problems in utilizing healthcare services. They could tell in depth information leading to receiving more valid data. Co-construction of a communal narrative was different from the data of phenomenology study because the participants

and the researcher enacted a mutual performance. Their engagement preserved subjectivity in the form of inter-subjectivity because participants' voices were respected and promoted the participants' role as authors of the meaning of healthcare experiences. The narratives from participant's interviews could shift the cultural view of participants from passivity to critical agency. In addition, the relational narratives shifted participants' view of themselves from frustration in the attainment of success to personal authority (Gadow, 1994; cited by Sakalys, 1999: 1473).

Gaining self-awareness and empowerment

After the interview was finished, participants could gain their new awareness and self-growth from their storytelling. They could move their stories outside the professional overview involving a profound assumption of personal responsibility and a sense of being-for-another (Frank, 1991; 1995; cited by Sakalys, 1999: 1472). They could use their narratives to advise their actions in healthcare confrontation next time. They also evaluated the interview that it could relieve their anxiety and enabled them to empower themselves because they could overcome sufferings and find the way to improve their health. They described good feelings about sharing information with the researcher that might in turn be shared with other health professionals or policy makers through publications and presentations (Hutchinson, Wilson and Wilson, 1994: 163). Participants who were volunteers and leaders provided a sense of purpose for the interview and care about the outcome. They hoped the data from them could be ultimately useful for the change and improvement of healthcare for every person living with HIV/AIDS in the future.

In addition, the participants were invited to contact the researcher as the address and telephone number were provided. They allowed the researcher to contact

them by mail and telephone as well. The next interviews were conducted whether the participants allowed the researcher to meet them. Some of the participants felt free to communicate with the researcher via telephone and mail. Thus, they could add more information or clarify any information they had given during the interview. The researcher received calls from participants living in Bangkok, Phayao, Surin, and Phuket who provided information, suggestions, and further recruitment.

Participant document data

Participant document comprised participants' information data, field-notes, and memos. The procedures for collecting document data were as follows:

1. Participants' information data

The investigator collected participants' information data at healthcare settings where participants went to utilize health services. This document data were treated as obtrusive data; thus, the researcher obtained the document under the permission of participants and the administrators of healthcare settings, in order to keep participants' confidentiality. Participants' document data were recorded from in-patient and outpatient charts, which presented the detail about illness and treatment history regarding HIV/AIDS. The documents of participant data were recorded using personal information data as a guideline. The detail of the guideline was explained in an obtrusive document (Appendix A).

2. Fieldnotes

Fieldnotes were recorded when the investigator interviewed and observed each participant in healthcare settings and their homes or residences. The information about participants' household, environment, and healthcare services was recorded after each visit and interview. In addition, participants' non-verbal content

was observed while engaging in in-depth interviews. Fieldnotes were also taken to document situations such as physical and emotional reactions, participants' characteristics, behaviors, verbal and non-verbal communication processes, expression, and any other issue in order to confirm the validity of data triangulation (Streubert & Carpenter, 1999: 301).

A fieldnote guide was used to record the observation of individuals and context occurrences (Appendix D). It was useful to remind the investigator to be regardful to places or settings, pattern of social relationships, emotional expression, general reaction, and non-verbal communication and behaviors and procedure problems. The photographs were also taken under the permissions of the healthcare staff and participants when doing activities in healthcare settings and home visits. The context and environment of each participant's home or residence such as family members and support, locations, and characteristic of daily living were taken in fieldnotes, so that the data could be used as methodology triangulation in data validity (Boyd, 1993: 460; Denzin, 1989: 243-244).

In the fieldnotes, the context and circumstances of each healthcare setting were also recorded, particularly healthcare provisions in each healthcare settings, the activities of healthcare staff regarding healthcare services, and the environments of healthcare. The fieldnotes and photographs were very useful as a reminder for the researcher when analyzing the results of the research.

3. Memos

The utilization of memos could help the researcher in development and formulation of the theory or knowledge (Strauss & Corbin, 1990: 197). Memos were written while going through the process of data collection. The written record of

memos referred to an analytic process, the date, and detail of each participant's story and recorded analysis related to healthcare services. The investigator wrote the discussion of tentative ideas and provisional categories, compared findings, and briefly wrote about the thoughts on this research. The memos contained details of each healthcare setting, the specific treatment, the general treatment, and the facilitating factors and obstacles of healthcare utilization of each participant. The memos were written in forms of diagram that could help the investigator to remind the analyst of the structure of the study and guide the concrete thinking. The usefulness of memo writing is that it could guide the researcher to think about the solutions of the findings during the analysis process. In addition, memos were used to compare different groups of characteristics of participants such as gender, geographic and socioeconomic background and types of health welfare.

Data Analysis

Data analysis was conducted by using narrative analysis of interviewed data. Then the analyzed data were synthesized by using structure elements.

The elements of writing synthesis

In the process of data analysis, the researcher analyzed the data of the participants' stories from each part of healthcare settings. Each analyzed data were synthesized by using structure elements from the writing of Stevens and other narrative researchers (Bell, 1988; Labov & Waletzky, 1967; Polanyi, 1985; cited by Stevens, 1992:103-104). These elements that were essential and adequate as a guide of a story were as follows:

1. Orientation: an agreeable beginning made up of statements that referred to functions such as telling person, place, time, or conductible conditions. These references introduced story action and are occasionally found all over the story.

2. Complication: the principal body of story action consisted of a series of episodes that were associated incidentally or by chance.

3. Evaluation: narration and elaboration excluded the action and made understanding of the circumstances. These statements demonstrated the storytellers' point of view, implied the relative significance of episodes and illustrated their attitudes towards the occurrences, persons involved, and contexts of the story.

4. Resolution: this was a recognizable conclusion wherein effects of a story were reported.

Narrative Analysis

In order to create a textual database, individual interviews from audiotapes and fieldnotes were transcribed verbatim. Some contents in interview data were rechecked by participants and the investigator. Written transcription and fieldnotes were reviewed several times by the investigator and experts. Data analysis was conducted by using narrative analysis for interviewing data and participants' document.

Narrative analysis in terms of macro textual analysis comprehended the verbalization and representation of society and group to words. Narrative analysis included consideration of the temporal order of circumstances, individual and group diversities, story frameworks, discontinuities in conversations and consistency within stories (Mishler, 1986: 66-95). The following questions advised narrative analysis in

this study: What kinds of stories were told? What ideologies were rooted in these stories about persons with HIV/AIDS' accessing healthcare systems? What contradictions existed within and between the various accounts?

Interview data and participants' document data were analyzed using a multistage analysis technique (Steven, 1993: 189-195; Steven & Doerr, 1997: 525-526). With each stage, purposeful consecutive reading of the interview transcripts was conducted to analyze story structure, context, content, and effects. A multi-staged narrative analysis was devised based on synthesis and extension of narrative techniques articulated by the investigator and experts. These stages were as follows:

1. Demarcation of the boundaries of each story: The interviews were transcribed and demarcated of the boundaries of each story. A story was operationalized as relating to a single healthcare encounter. To designate text as story, specific structural components were necessary, including orientation, plots, evaluation, and determination. The stories in the data were identified, and their frameworks were indicated in all the interviews. Each story was analyzed and synthesized, its structure element distinguished and characterized, and its situational context accounted. The researcher could find out 475 healthcare stories in the data across all interviews. In this stage, 475 stories about access to healthcare systems, both positive and negative experiences were described and became the units of analysis.

2. Analysis and examination of each story: story contents and contexts were analyzed by examining each participant's story and participants' recounting of what happened in accessing the healthcare system. The researcher paid attention to each case of healthcare concern prompting the HIV/AIDS persons to healthcare, their

expectations and needs, environmental conditions, disclosed action, consequences, and their interpretations of and responses to what happened. Adequate paraphrases were constructed to assist this process. An adequate paraphrase was a condensed narrative of verbatim story that incorporated the main plot and context of action, the people and the interaction involved, and participant's evaluation of story occurrences. During this stage, experiential themes were identified and elaborated.

3. Search for similarities and differences: participants' experiences in healthcare access were searched for similarities and differences among individual participants and among sample subgroups. This method was accomplished by constructing visual and written synopses of each narrative that could compare and contrast the stories to distinguish the difference of healthcare circumstances and meanings. The investigator compared and contrasted stories according to persons with HIV/AIDS's demographic characteristics such as health status, cultural background, geographical data, and socioeconomic contexts.

4. Re- examination to find narrative extracts: The stories of persons with HIV/AIDS's experiences in accessing healthcare system were re-examined to find narrative extracts that best irradiated analytical findings.

In the step of comparative examination, the researcher compared how 475 healthcare stories for 50 narrators differed among individuals and among subgroups. The researcher used the questions posed in this step of data analysis: Do persons with HIV/AIDS in each part have different or same difficulty in accessing healthcare? Do different health welfare and supports affect persons with HIV/AIDS? Do persons with HIV/AIDS who have different health statuses expect and need different healthcare?

Are there aspects of healthcare experiences similarly or differently reported regarding socioeconomics, cultural, and geographical environments of HIV/AIDS participants?

At the end of data analysis, the researcher could gain the reality of experiences in healthcare in the large group of persons with HIV/AIDS in the historical context of larger social, political, and economic impacts. Using narrative analysis, the researcher could develop better understanding of individual experience leading to collaborative relationship and political implications embedded in storytelling.

Non-narrative analysis

1. Content Analysis

The document data and non-storied data of individual participants provided background, explanation, elaboration, and extension of the storied data. Thus, they were used as contexts in the story and narrative analysis. The document data and non-storied data were analyzed using thematic content analysis coding and category clarification (Loftland & Loftland, 1984; Miles & Huberman, 1994: 69-78). Themes and categories were clarified by representing their properties, processes, antecedents, consequences, and the conditions under which they functioned. Data coded for a category was compared with the other data coded for that same category. The researcher made an attempt to conceptualize the full range and variation of information that was categorized similarly.

2. Document Analysis

Document analyses were used to analyze document data. Each document related to national health care policy, health care system and regulation in Thailand and other countries were read for identification of major themes surrounding the theoretical base of Habermas' critical theory (Haberman, 1971: 309; Hiraki, 1992:

4-8). Themes referring to the concept of dominant will be organized and explicated in terms of power such as access, equity, justification and accessibility. Critical analyses of comparing and contrasting are the bases of the categories and themes.

Self as a part of data analysis device

This study used critical perspective as the worldview of understanding experiences of the disadvantaged group in utilizing healthcare systems and critiqued the dominant power of healthcare that affected them. The research goal was to generate the knowledge in terms of policy that could be used to alleviate oppressive suffering and contribute to improving persons with HIV/AIDS's health. The transferability and validity of this study was based on the investigator's worldview because the investigator used herself as a part of data analysis.

The background of the investigator is a middle class family with limited resources and support. The investigator has grown up in the environment of constraint and has had to make an effort to accomplish the goal of life such as education and profession. The investigator has been successful in education because the educational structure has the system to support the low-income students. The investigator thinks that if society has a quality system to facilitate and provide for the disadvantaged groups, they will have the equal right of basic needs to maintain their safety and health in society.

The investigator has been a volunteer and worked for disadvantaged groups such as farmers, the poor people, and laborers in remote areas and communities when she was a nursing student. The investigator has had direct experiences in facilitating them by responding to their problems, supporting and giving advice to them on health

information and voice for their equal rights. These experiences have made the investigator gain the understanding of social problems experienced by the disadvantaged groups and inequity of society influencing those who are struggling. This perspective enhances the investigator to have critical eyes in looking at both disadvantaged group and social problems leading to having sympathy with the disadvantaged group. If opportunity arises, the investigator has the determination to voice and advocate for those who are oppressed.

In the healthcare arena, the investigator has worked as a professional nurse and nursing instructor for 20 years. The investigator has seen the phenomena of the patients who suffer and are not satisfied with health services because of the ineffective healthcare system. Healthcare systems are not equal for disadvantaged groups, in particular the poor, HIV/AIDS patients, women, and children. The investigator always advocates and facilitates them to meet their needs and improve their health. However, this facilitation is performed only for the individuals and is not sustainable for the general public. The investigator would like to try to involve the improvement of a healthcare system in society.

The investigator has worked as a healthcare provider and tries to provide effective care for the patients. However, providing quality and equity health services is limited because the systems do not facilitate the health staff to work in the constrained environment. The investigator has gained the information of healthcare reform in the national symposium. The policy makers try to solve the problems of inequality and unjustified healthcare for disadvantaged groups among the Thai people.

However, the channels of accessing the information are different. The healthcare systems will be improved through a reform of the health policy. The

information of healthcare providers and systems can be investigated by studying the documents related to healthcare policies in many sources. However, the information from the part of disadvantaged groups has not been adequately investigated. Thus, the study of the experiences of disadvantaged groups in accessing healthcare systems will help enrich information in generating healthcare policy that responds to the needs of disadvantaged groups. Healthcare systems should be reformed for equality, efficiency, and accessibility for disadvantaged groups in cooperation with multi-disciplinary healthcare teams.

Trustworthiness

Before conducting this study, the investigator used herself as an instrument (Morse & Field, 1996: 116). In order to gain the ability of qualitative researcher, the investigator had to study qualitative methodology for one semester and had to study a short course of data analysis of qualitative research from the qualitative association. In addition, the investigator had to practice and do a pilot study to improve the capability as an interviewer such as establishing rapport to gain trustworthy information, listening, and reflecting skills to gain an in-depth interview without researcher bias.

Trustworthiness is a fundamental issue to evaluate the quality of qualitative research that the inquiry findings are worthy or worth taking into account (Lincoln & Guba, 1985: 289-331; Morse & Field, 1996: 118). The trustworthiness used as a guideline in this study was based in Lincoln & Guba's criteria (1985).

Lincoln & Guba's criteria comprised of credibility, transferability, dependability and confirmability. These criteria were applied as guidelines to demonstrate the trustworthiness in this study as follows:

1. Credibility: internal validity in empirical research is insiders' experiences.

It is based on the capability of the investigator to enhance credibility. Prolonged engagement, persistent observation, and triangulation are the activities to increase the probability that leads to credible findings.

In this study, data confirmation was conducted by using member checking. Participants and other interviewees were good facilitators in data validation in the same healthcare settings because they had known each other very well. Participants who were HIV/AIDS volunteers provided the direct test of findings and interpretation. They felt honored to be involved in this study because this research could gather accurate data. The next interviews were also conducted whether participants required and could validate more data analysis. In addition, all data analyses were checked and investigated by experts (Lincoln & Guba, 1985: 319-323; Young & Stewin; cited by Streubert & Carpenter, 1999: 29).

2. Transferability: the research finding is relevant and has general similarities able to be applied under other conditions, contexts, or occurrences with other groups. The results of this study could examine the same phenomena of accessing healthcare system but in different contexts and then compare and contrast the results (Lincoln & Guba, 1985: 317; Morse & Field, 1996: 118, 120; Holloway & Wheeler, 1996: 168).

The researcher checked the consistency of the story with other stories from other participants at different healthcare settings. The data interpretations re-examined

the relation to basic research questions and overall research purpose. Furthermore, the analytical results in this study were compared to the results of other investigators. Thus, the researcher recorded the findings as memos and discussed them with other researchers.

3. Dependability: reliability or external checks of empirical study were used. It refers to the clarity and reproducibility or conformity of the researcher's methodological and analytic decisions and interpretations of data (Sandelowski, 1986: 27-28). In this study, an audit trail was developed between the investigator, the academic advisor, and experts. The reproducibility of methodology and the interpretation process were conducted by the investigator under supervision of the academic advisors as well as experts in order to assure the consistency of the interpretation process.

4. Confirmability: the valuation of confirmability depends upon the quality of data that is objective information from participants rather than from the investigator (Morse & Field, 1996: 118). Therefore, prolonged contact with participants and long periods of observation were used. In addition, the investigator used the memos and consultations with the academic supervisor in order to reconfirm the raw data without investigator bias.

Protection of Human Rights

As HIV/AIDS infection is a sensitive issue in societies, people living with HIV/AIDS feel prejudiced by society and have a lot of impacts on utilizing necessary services in society, especially healthcare services. Therefore, the investigator was aware of this and careful in collecting data from participants with HIV/AIDS.

Consideration of ethical issues in this study was performed seriously in order to protect human rights by following the description below (Halloway & Wheeler, 1996: 39-51; Patton, 1990: 356-359):

1. Ethical committee consideration and permission

Before conducting the research, formal letters asking for permission to collect data from the Faculty of Graduate Studies, Mahidol University, were sent to institutions such as hospitals, and secondary and primary healthcare settings in the selected provinces (see Appendix E). In addition, the investigator was accepted and allowed to collect data from ethical committees by formal communication. For this reason, healthcare providers in each institution well cooperated and facilitated the researcher.

2. Protection of HIV/AIDS identity

The researcher could not conduct this study unless participants with HIV/AIDS were endorsed and introduced to participate in the project by the facilitators who were nurses and persons with HIV/AIDS. These were confidential because HIV/AIDS participants voluntarily disclosed themselves and felt free and comfortable. They were interviewed at a private room or counseling room so that participants with HIV/AIDS did not have to expose themselves. In addition, participants who offered their houses or residence for interviewing were also kept confidential. Therefore, the researcher visited their house in form of a private visit instead of a formal visit.

3. Oral and paper informed consent

The explanation and description about the purpose, the method, and the benefits of participation in this study were given to HIV/AIDS participants. They showed informed consent in terms of oral or paper consents at the beginning of the study. First, they would be asked for permission to obtain audiotape the interviews. The participants might withdraw from the study and left the researcher with an incomplete set of data. Each participant was also told that they could decline to answer any issues or points that were sensitive. If they were interested in asking any questions, checking or seeing the information in this study, they could do so. After interviewing, the participants were asked for permission to explore the stories and check the transcription of the data from the tape. Information sheets for participation can be found in Appendix F.

4. Keeping confidentiality and respect for participants' anonymity

The stories were kept confidential and the participants' anonymity was respected. The investigator disclosed the participants' names during the interview and tape recording. After the research was submitted, all the interview data from the tape cassettes were destroyed. The investigator's address and telephone number was given to participants; therefore, they could communicate with the investigator and ask questions. In addition, participants were free to communicate with the investigator via any modes such as letters and telephones to keep relationship and to re-interview.

5. Empowerment and contribution

There were no costs to participants. However, participants would receive reimbursement for time and transportation. As for the benefits of this study, the participants could tell the story about their experiences in accessing the healthcare

system and gained their autonomy and self-esteem. Participants would gain empowerment during the interview because they were encouraged to speak for themselves. Participants contributed to develop reflection and were free from constraints. Their stories would inform recommendation of healthcare policy for people living with HIV/AIDS.

Summary

In conclusion, this research utilized a narrative interpretative design to dialectically understand the disadvantaged groups, particularly HIV/AIDS persons, in accessing the healthcare system and critiqued domination in terms of healthcare policy that affected the consumers' health and well-being in society. The purposive sampling and target chained referral technique of 50 participants were applied. Interview data and documents related to the healthcare system were collected. The data were analyzed using narrative analysis. In the process of data collection, informed oral or paper consent was obtained from each participant. Confidentiality and rights of all participants were highly regarded and protected.

CHAPTER IV

FINDINGS PART I: STRUCTURAL CONSTRAINTS IN HEALTHCARE SYSTEMS

This chapter presents the results of data analysis consisting of the study of Thai healthcare policies for persons with HIV/AIDS, participant information data, and study findings. Participant information data consist of general information of participants followed by demographic data including income and payment of healthcare as well as participants' history of illness. The study findings present the results of narrative analysis of the interview data and describe the structure constraints in healthcare systems for persons with HIV/AIDS.

Study of the Thai healthcare policy for persons with HIV/AIDS

Recently, Thailand has the National AIDS Plan (2002-2006) under the ninth National Economic and Social Development Plan (2001-2006), and the strategic plans have been managed continuously following the former national AIDS plan (1997-2001). Document analysis of the Thai National AIDS plan was categorized into 2 categories: 1) The Thai National AIDS plan compared with that of developed countries, and 2) The Thai National AIDS plan compared with that of developing countries.

The Thai National AIDS Plan compared with that of developed countries

From the document analysis, it was found that the active strategy of Thai National AIDS Plan was not well developed and proceeded because care and services for HIV/AIDS

were not demonstrated and guided by the policy makers. Therefore, the Thai National Plan for AIDS was analyzed and compared with other national plans. It was found that the care and service policy in Thailand is lacking in the following points:

The budget of care and treatment

In developing countries such as the U.S.A., a large budget is spent for healthcare expenditure, about 13.7% of Gross Domestic Product (GDP) (WHO, 2000a: 195). The Food and Drug Organization has an important role to approve the quality of anti-retroviral medicines and other medicines for AIDS treatment. Furthermore, the government spends more budgets, about 221 %, on the treatment in the form of anti-retroviral medicines to promote the people living with HIV infection's access to care at the early stage of the disease. In addition, the central government has founded the office of AIDS research and increased the budget, about 50%, for the research and development of HIV/AIDS care and implementation.

In contrast, in the former Thai National AIDS Plan, Thailand spent more budgets on AIDS prevention than curative care, at 64% versus 36% of AIDS expenditures. The total AIDS-related amount was a modest proportion--about 6% of the overall public health budget (Shepard, 2000: 2). Furthermore, in 2001, HIV/AIDS program spending was equal to 0.16% of the total government spending, or only US\$ 0.54 per capita (The Office of National Economic and Social Development Board; cited by Teokul, W., 2002: 12). It demonstrated that the budgets spent on HIV/AIDS care were inadequate. The Thai national AIDS plan mainly focused on AIDS prevention so that the government faced with care burden of many patients with symptomatic AIDS.

The resources management of care and treatment

In the U.S.A., the government has established a national plan and policy by promoting people with HIV/AIDS to have the capability to access the care and treatment in the early stages of the disease. Furthermore, the government establishes healthcare funding of medical coverage by founding Medical Programs and The CARE ACT Program to promote and support patients with a low income and people who do not have healthcare security or insurance. For these reasons, patients with a low income can have access to the treatment of anti-retrovirals, tuberculosis, mental illness, and drug addiction in the community healthcare settings (The White House, 2000b: 1-8).

In Thailand, the government has established several financing schemes such as social security welfare, the civil servant medical benefit scheme, and the public healthcare scheme that cover the treatments and care for Thai people. However, the coverage of AIDS treatment is excluded. Although the national AIDS plan supports budgets for AIDS treatment, less than 1% of persons with HIV/AIDS could receive free anti-retroviral therapy via the project (BBC NEWS, 2000: 1). The Thai National Plan for AIDS lacked the practical strategic plan in resource management of care and services for low income people to access early treatment and continuity of care such as granting a budget for women, children, and people living with HIV/AIDS who do not have healthcare insurance. In addition, there is no strategic plan regarding funds and resource allocation for the public and communities to provide basic care and services. The services provision for treatment and care of tuberculosis, drug addiction, or mental illness lacked integrating services and quality care as well as case management in community-based care and/or primary healthcare.

The support services for chronic illness

National AIDS plan of the U.S.A was established to improve and promote people with HIV/AIDS to have a better access to healthcare systems. For instance, Global AIDS and Tuberculosis Relief Act of 2000 has been established to prevent the problems of the epidemic of tuberculosis in HIV/AIDS. In addition, Disability Act has been founded to facilitate the care and support for patients with chronic illnesses who are unable to work. This Act defines AIDS as a chronic disease. Thus, people living with AIDS can be supported by the Disability Act (The White House, 2000b: 1-4; The White House Press Office, 2000: 2).

In Thailand, there are no measures to reform or establish a policy or act to assist people living with HIV/AIDS to use their rights to gain social support, care, and treatment. For example, there was no strategic plan for improving the rehabilitation and disability act and assuring private insurance. In the Thai National Plan for AIDS, there is no fund to support care and services such as improving social security and health insurance and workmen compensation for people with HIV/AIDS because rehabilitation and anti-retroviral medicines and expensive medication are not covered for HIV/AIDS laborers.

The strategic plan for continuing human resource development

In developed countries, the strategic plans to improve quality of care are a main focus to distribute equal and quality of care to people living with HIV/AIDS. The programs are implemented such as increased training for healthcare professionals and greater accountability through the use of performance measures for quality care. The health professional such as experts of AIDS treatment and care are trained to provide standard healthcare services at community health settings and primary healthcare (NAT, 1996;

Associate of NHS providers of AIDS Care and Treatment, 1997; cited by National AIDS Trust, 1998: 3)

The Thai health policy lacks clear-cut strategies in development and improvement of the healthcare providers' capabilities to care for HIV/AIDS persons including training programs for updated treatment and care for physicians and nurses and other healthcare providers in the local health settings and the community health settings.

The guideline of quality and standard treatment and care

In developed countries, there is improving program coordination with integration services, with primary and collaborative efforts with private sectors and multi-levels of healthcare setting. The National AIDS Plan emphasizes the improvement of quality of care such as investigating options to produce a comprehensive and up-to-date evidence base accessible to all stakeholders such as publics and community. In addition, the government has constructed clinical guidelines and treatment standard to ensure equitable access to treatment, monitoring and testing for people with HIV/AIDS. The plan of treatment and care also includes the support and fosters adherence programs for HIV/AIDS treatment as well as development of new national direction on standard of treatment and care of children (The White House, 2000b: 1-6). In the United Kingdom, the healthcare services emphasize the development and improvement of the compatible referral pathways from specialist HIV services and mainstream public healthcare services. The healthcare services are built on the foundation for AIDS work on service standards and networks to ensure the best possible use of resources for treatment and care under the new funding distribution (National AIDS Trust, 1998: 5-8).

In Thailand, the measures for stipulating standards and guidelines of treatment, care, and services including enhancing the potential of healthcare providers in primary

healthcare and the community are not well implemented. Furthermore, the policy of increasing health providers' distribution, in order to expand care services in communities, is not yet settled. The policy of care and services for HIV/AIDS lacks comprehensiveness and continuum of care such as establishing an effective ambulatory care system and home healthcare system instead of an acute care system. In addition, the policy does not inform healthcare providers of how to promote persons with HIV/AIDS's access to care in the early stages of the disease. The strategy lacks practical coordinate continuum of care among the healthcare profession and collaboration of organizations in communities.

Monitoring and evaluation of AIDS treatment and care

As regards, the National AIDS plan in developed countries, there are the strategic plans for evaluating program effectiveness such as providing precious information for planners and those on the front lines of the outbreak and support in providing superior care to persons living with HIV/ AIDS. In order to expand the quality of treatment and care in the community healthcare setting and to utilize limited resources, the plan includes the establishment of a mentoring system and program for improvement of the skill of physicians, nurses, and related professionals. To evaluation the cost effectiveness of treatment and care, the strategic plan has established the measure of monitoring the standard of HIV/AIDS care, communication and exchange of skills and deliver full range of appropriate services in order to provide equal access to a continuum of services and information. The strategic plan also addresses the evaluation and the information of standardized anti-retroviral therapies and coordinated services meeting up-to-date standards of care for each people with HIV/AIDS at the community care level (Australian National Council on AIDS and

Related Disease, 1999: 145; Commonwealth Department of Health and Aged Care, 1999: 9; The White House, 2000b: 6-7).

In Thailand, the strategy of assuring effective use of limited resources for HIV/AIDS care is not set up. In addition, the addressing of the implementation of policies such as the cost effectiveness, quality of care and healthcare assurance is not evaluated and/or followed up to improve the next strategic plan.

The Thai National AIDS Plan compared with that of developed countries

The study of the National AIDS Plan in developing countries such as South Africa, India, Pakistan and Thailand reveals that there is a lack of equality policy for HIV/AIDS treatment and care at a national level. Therefore, the Thai National Plan for AIDS was analyzed and compared with other national plans in developing countries. In addition, it was found that the care and service policy in Thailand was similar to those in other developing countries in the following points:

Inadequate budget of HIV/AIDS treatment and care

The inadequate and unclear policies of budgets are major barriers and constraints to access effective care and treatment. In particular, the National AIDS Plan in developing countries focuses on AIDS prevention; thus, the budgets for treatment and care are not mentioned, and they are inadequate to improve the quality implementation of AIDS treatment and care. From the study of the budget for HIV/AIDS in Tanzania, and Ivory Coast in Africa, Thailand in Asia, and Mexico and Brazil in South America, it was found that the government had spent the lowest share of their health expenditures on HIV/AIDS. The shared of health expenditures devoted to HIV/AIDS was only 1.5% in Thailand, 1.8% in Mexico, and 6.7 % in Ivory Coast (Shepard, 1997: 3-4).

Lack of tangible strategic plan for resources mobilization

The policies in developing countries and Thailand lack tangible strategic plans regarding resources mobilization, planning, and advocacy skill for healthcare professionals, HIV/AIDS caregivers, and volunteers in local and community levels. The strategic plan of the primary mode of delivery care and support is not clear-cut. The mention of home and community care in Thailand, Bangladesh, India, and Pakistan is not apparent, and only the level of government support and management for this approach is mentioned (Furber, 2001: 1-2). In addition, the strategic plan for human resource preparation and development such as experts of AIDS treatments and care is not addressed and evaluated for the quality of human resources for HIV/AIDS care, especially in community healthcare settings. In addition, the strategic plan did not mention the method to improve an understanding of human right issues to increase awareness of healthcare providers and people in community.

The issues of right to health and right to access to equal treatment and care

The issues of right to health and right to access to equal treatment and care still lack the affordable, available, and appropriate method to prevent AIDS progression and evaluation on strategic planning (AF-AIDS / ICASA, 1999: 5-9; The National AIDS Control Organization, 2002: 6-7; Khan & Hyder, 2001; 215-217; Nation AIDS Committee, 1997: 30; 2002: 30-31). All developing countries have proposed an appropriate level of care and treatment recommended by WHO/UNAIDS in terms of the key elements in HIV/AIDS care and support (WHO/UNAIDS, 2001: 15-17). However, there are not tangible issues of the strategic plans to implement the care and support that promote standardized, equal, and quality treatment and care for anti-retroviral therapy, tuberculosis, and opportunistic infection in multi-levels of healthcare settings.

Lacking framework for ensuring equitable distribution of resources for AIDS care

The National AIDS Plan in developing countries lacks a framework for ensuring equitable distribution of resources for AIDS care and treatment (National AIDS Control Program, India; National AIDS Control Program, Pakistan; Ministry of Health and family Welfare, Bangladesh, National AIDS Committee, Thailand). Also, the National AIDS Plan lacks the addressing of important healthcare structural such as healthcare financing, healthcare coverage, and specific support for disadvantaged groups including the management of sustainable resources. The health policy for AIDS prevention should be in accordance with the distribution of anti-retroviral therapy to improve primary and secondary prevention services and distribute quality of comprehensive health services such as community and home-based care. The framework of implementation and evaluation of the strategic plan to distribute the resources lacks guidelines and monitoring system as well.

Demographic data of participants

Demographic data on 50 participants were obtained through close-ended questionnaires and are summarized in Table 1. The participants were 30 females and 20 males living in 5 different parts of Thailand. The mean age was 31.8 years (S.D.=5.75), ranging from 22 to 54. Almost three-quarters of the participants (33) were widows as their spouses had died from AIDS. About a half of the participants (27) had their hometown in the countryside or suburban areas far from their current residence in each province. Furthermore, almost half of the participants (11 females, 10 males) living in Bangkok, Phayao, Rayong, and Surin had completed only primary school or grade 6. Only eight (16%) and six (12%) of the participants living in

Bangkok and Phuket graduated with a diploma and a bachelor's degree, respectively. More than half of the participants (32) had monthly income less than 2,000 Baht and were in debts due to loans (5,000- 1,000,000 Baht) from relatives and other resources in communities. About a half, or 54%, of the participants (27) were unemployed or worked as a farmer without monthly income. Only 26% of the participants (13) received fund for living of 500 Baht per month and received educational fund for orphans from social welfare.

Table 1. Demographic characteristics of participants classified by provinces (N=50)

Demographic Characteristics	Bangkok (N=10)	Phayao (N=10)	Surin (N=10)	Rayong (N=10)	Phuket (N=10)	Total (N=50) (100%)
Gender						
Male	5	3	4	5	3	20 (40)
Female	5	7	6	5	7	30 (60)
Age (year)						
Less than 25	1	-	1	3	1	6 (12)
25-29	2	2	3	3	2	12 (24)
30-34	4	4	4	2	2	16 (32)
35-39	1	3	2	1	3	9 (18)
40 or older	2	1	-	1	3	7 (14)
Marital status						
Single	3	2	-	-	-	5 (10)
Marriage	1	1	3	4	3	12 (24)
Widowed/ Separated	6	7	7	6	7	33(66)
Hometown						
Countryside	6	-	6	7	8	27(54)
Municipality	4	10	4	3	2	23(46)

Table 1. Demographic characteristics of participants classified by provinces (N=50)
(Continued)

Demographic Characteristics	Bangkok (N=10)	Phayao (N=10)	Surin (N=10)	Rayong (N=10)	Phuket (N=10)	Total (N=50) (100%)
Educational level						
Grades 1-6	1	6	8	6	-	21 (42)
Grades 7-9	4	1	2	3	1	11 (22)
Grades 10-12	2	3	-	1	5	11 (22)
Diploma	2	-	-	-	2	4 (8)
Bachelor's Degree	1	-	-	-	2	3 (6)
Income (Baht / month)						
< 2,000	6	7	8	7	4	32 (64)
2,001-5,000	2	2	2	1	3	10 (20)
>5,001-10,000	1	-	-	2	-	3 (6)
>10,000	1	1	-	-	3	5 (10)
Economic status						
Indebted	5	5	7	7	6	30 (60)
Poor	4	2	2	2	2	12 (24)
Fair	1	3	1	1	1	7 (14)
Good	-	-	-	-	1	1 (2)
Supports/ Resources						
Social welfare	3	5	3	1	1	13 (26)
Family	2	3	3	2	7	17 (34)
NGO	3	2	2	2	-	9 (18)
None	2	-	2	3	2	9 (18)
Occupation						
Unemployment	4	7	6	5	2	24 (48)
Volunteer	2	2	1	2	1	8 (16)
Employee	1	-	-	2	4	7 (14)
Farmer	-	-	3	-	-	3 (6)
Own business	1	-	-	1	2	4 (8)
Gov. officer	2	1	-	-	1	4 (8)

Table 1. Demographic characteristics of participants classified by provinces (N=50)
(Continued)

Demographic Characteristics	Bangkok (N=10)	Phayao (N=10)	Surin (N=10)	Rayong (N=10)	Phuket (N=10)	Total (N=50) (100%)
Type of family						
Extended family	-	10	7	2	4	23 (46)
Nuclear family	10	-	3	8	6	27 (54)
Number Children in family						
None	5	4	-	1	1	11 (22)
1-2	4	6	8	7	6	31 (62)
3-4	1	-	2	2	3	8 (16)
Type of residence						
Own house	1	2	4	-	5	12 (24)
Family's house	4	8	5	4	2	23 (46)
Rented House	5	-	1	4	3	13 (26)
Hospice (NGO's)	-	-	-	2	-	2 (4)
Financing schemes						
Health welfare	-	4	4	-	-	8 (16)
Social security	1	1	-	1	4	7 (14)
P.H.C. scheme	-	4	6	4	3	17 (34)
Health welfare for State Employee	2	1	-	-	1	4 (8)
None	7	-	-	5	2	14 (28)

More than one quarter, or 34% (17), of the participants received social support from family members like spouses, parents, and relatives in the form of money or products from farm for daily nutrition. Only 16 of them claimed that they did not have any support from social welfare and family. Each participant who was both widowed and married had 1-2 children. All 72 children's ages ranged from two to 21 years old. About 8.3% (6) were HIV/AIDS infected. Two children in Phayao and Phuket died because of AIDS. Moreover, four of the children living in Bangkok, Phayao, Surin, and Rayong had symptomatic AIDS with opportunistic infection. Furthermore, 77.8% (56) of children were HIV negative, and only 12.5% (9) of these children received anti-retroviral therapy while being a fetus. Most of the participants (23) who lived in Phayao, Surin, and Rayong stayed in their family's houses in the countryside, while two participants (4%) who did not have any support from families stayed at Hospice managed by NGO's in Rayong. About a half of the participants, or 54%, had a nuclear families. One-third of the participants (36%) living in Phuket, Phayao, Rayong and Surin had financing schemes like public healthcare scheme or a 30-Baht gold card. Only 16% (8) had social welfare scheme for those with low income. About 28% (14) of the participants, seven living in Bangkok and seven migrant workers living in Phuket and Rayong, had no financing health schemes. Most of the participants especially those living in Bangkok received support for payment of treatment and medicine from social welfare unit in hospitals.

Participants' history of illness and health service utilization

Information concerning participants' history of illness was collected through closed-end questionnaires and in-depth interviews (See Table 2). Almost all of the participants (48) reported being infected with HIV by sexual transmission. Only two participants were infected with HIV by intravenous drug use (IVDU). Only one-fifth of the participants (11) had asymptomatic AIDS, and more than three-quarters of them (39) had been diagnosed with symptomatic AIDS with more than one symptom. In particular, 29.5% of symptomatic AIDS participants had been diagnosed with Pulmonary Tuberculosis (TB), 45.5% with Pneumocystic Carinii Pneumonia (PCP), and 22.7% with Cryptococcal meningitis. The mean length of time since being firstly informed that they were HIV sero-positive was 6.1 years (S.D.=2.9), with a range of 1.8 years to 14 years. The primarily reason for blood testing was performed in antenatal care including spouses' blood testing in 40% of the participants (20). Only five participants had blood test for health check-up before applying for work. Moreover, half of the participants had known that they were HIV infected when they had symptoms or illness and they had never been investigated or monitored their immunity like CD4+ cell count. The range of CD4+ cell count was 25 to 860. Seven participants (14%) had CD4+ cell count more than 200 cells / μ l.

Table 2. Participants' present history of illness classified by different provinces (N=50)

Demographic Characteristics	Bangkok (N=10)	Phayao (N=10)	Surin (N=10)	Rayong (N=10)	Phuket (N=10)	Total (N=50) (100%)
Mode of transmission						
Sexual	8	10	10	10	10	48 (96)
IVDU	2	-	-	-	-	2 (4)
Time of being informed HIV + (Years)						
1-3	1	1	1	2	1	6 (12)
>3-5	2	3	5	3	4	17 (34)
>5-10	4	5	3	4	3	19 (38)
>10	3	1	1	1	2	8 (16)
Stage of Disease						
Asymptomatic	1	1	3	2	4	11 (22)
Symptomatic	9	9	7	8	6	39 (78)
Reasons for Blood Test						
Illness	4	4	4	6	-	18(36)
ANC Blood test	4	4	5	4	3	20(40)
Health check-up	-	-	-	-	5	5 (10)
Spouse's illness	2	2	1	-	2	7 (14)
AIDS Symptoms (> 1 symptom / case)						(N=44) (%)
TB	3	3	2	4	1	13(29.5)
PCP	5	4	4	4	3	20(45.5)
Fungus Meningitis	3	3	2	-	2	10(22.7)
Cancer	1	-	-	-	-	1 (2.3)
CD4+ (cell/ μ l.)						
<200	7	3	3	1	4	18 (36)
>200	1	-	-	2	4	7 (14)
No Check	2	7	7	7	2	25 (50)

Table 2. Participants' present history of illness classified by different province (N=50) (Continued)

Demographic Characteristic	Bangkok (N=10)	Phayao (N=10)	Surin (N=10)	Rayong (N=10)	Phuket (N=10)	Sum (N=50) (100%)
Treatment						
Symptomatic care	5	7	8	9	9	38 (76)
ARV therapy	5	3	2	1	1	12 (24)
Type of service utilization (> 1 service/case)						(N=50) (%)
Day care	2	10	10	-	8	30(60)
Out-patient	10	10	10	10	10	50(100)
In-patient	4	8	10	7	8	37(74)
Emergency Room	7	4	8	3	2	24(48)
Home Care	2	-	5	-	-	7 (14)

Participants who were treated with anti-retroviral therapy (ARV) accounted for only 24% of the total participants (12). Five participants living in Bangkok, only one participant living in Phuket, one living in Rayong, three living in Phayao, and two living in Surin were treated with anti-retroviral therapy. All of the participants (50) utilized healthcare services at out-patients departments, and half of the participants (26) had utilized health services at emergency rooms. Most of the participants in Phayao, Surin, and Phuket also utilized Day Care services in community healthcare and hospitals. Only two participants in Bangkok utilized day care services in hospitals for treatment of fungal infection. Participants who lived in Rayong never utilized Day Care at the hospital. Only seven (14%) of the participants utilized home care services which were provided by a community hospital in Surin and a university hospital in Bangkok.

Structural constraints in healthcare systems

Fifty participants reflected their experiences in accessing healthcare services. Not only did each participant recall their stories of utilizing healthcare, they also reflected the stories and experiences of their HIV/AIDS members. In the narrative data of the participants, they told their experiences from when they were first informed that they were HIV infected by healthcare personnel until the present time. All participants narrated that they had positive and negative experiences in utilizing healthcare services. They told about factors that either hindered or facilitated them in accessing the healthcare system. Seventy percent of the narratives from the participants expressed the experiences of what they suffered in access to healthcare services. Thirty percent of them narrated what they were satisfied with the access to healthcare systems. However, they narrated their experiences in healthcare and described them in terms of structural constraints in healthcare system which could be divided into 4 categories: service provision constraints, constraints of treatment and care, sub-standard healthcare environments, and healthcare coverage constraints. The findings are described and exemplified with details and verbatim extracts from participants' stories (names used were pseudonyms) as follows:

Service provision constraints

Almost all of the participants who had negative experiences in access to healthcare system were symptomatic AIDS patients with chronic diseases of Tuberculosis, P.C.P, fungal meningitis and other infections related to low immunity. Participants told the stories about the service provision constraint that hindered them from receiving health information and treatment including continuity of care. The

participants narrated service provision constraints in four subcategories: disclosure of AIDS status by separating service areas, limited attention from healthcare providers, lack of experts for specific care and treatment, and being interned in life threatening services.

Disclosing AIDS status by separating service areas

The arrangements of care in wards were the factors that made a person living with HIV/AIDS unsatisfied with the services. Generally, the service provision for caring for the patients separated HIV/AIDS and none-HIV/AIDS patients in the same ward into sections. The poor patients had no choice and had to endure other patients and their families' objections. It was convenient for healthcare staff to provide a special care and treatment for patients with HIV/AIDS, but this kind of services revealed their status directly. A participant, Mit, raised this problem and felt that he was cared for without dignity. He was depressed and anxious as he was treated with discrimination. He expressed his story and its negative consequences like this:

Of course that place had no special rooms. I just slept when I was there. Every patient slept in the same room, but there was a separation between non-infected and infected patients. I questioned in the provincial meeting and the response was that it was easy to provide care. Well, it was reasonable. I accepted that. I wondered if the reason was justified to separate the patients. It was like a sign telling you that the patients on that side were AIDS infected. The patients' relatives who were there often knew it, but the new ones may wonder. It was a depressing place. If I had to stay longer, I might no longer be others' burden. I thought of killing myself. I demanded to be transferred to another private hospital.

M2Phu, 279-282/ 25

Female participants who were hospitalized for delivering babies described the experiences of separated care in the postpartum ward. The isolation of care was used to prevent infection in the same ward while the persons with HIV/AIDS were disclosed of their status leading to negative impact from others. A 28-year-old

participant expressed her feeling when she was rejected from the other postpartum women near her bed:

At that time, my relatives did not know I was HIV infected. I did not want my son and them to know my AIDS status. I was embarrassed why they [healthcare providers] had to hang the red bags at the end of my bed. They should separate the red tank for us and told us to put the used objects in the bathroom. ...They should not hang the red bag at our beds. It seemed to reveal our status to everyone who visited the hospital. They would know that we had been AIDS infected. I did not feel pity for myself but I felt pity for my husband and my first son when other people looked at us...I was rejected by the woman who stayed next to my bed. She asked whether I had AIDS infection. Then I said 'yes'. She denied lending me a spoon. She did not talk with me after she knew my illness.

Fe4 Phu, 341-347/10

Limited attention from healthcare providers

Most of the participants described the service provision in health institutions that were inadequate attentions from healthcare providers. Participants who had experiences in hospitalization and had severe illness did not have immediate care from healthcare providers. For example, they often faced with such events that nurses could not help them relieve the severe headache because there was no doctor around to prescribe more effective pain relieving medicine at nighttime. Thus, they perceived that healthcare providers were negligent in taking care of them.

Dao, a 28-year-old female who had severe headache from cryptococcal meningitis expressed how helpless she felt:

The nurses here? They're good...good enough. They're also serious.... I want them [nurses] to be patient because they were trained to provide care. But the ultimate need is that I want the clients to be more patient...because the doctors [nurses] are also tired. I saw them run hurriedly. For me, since I was in hospital, I only cried when I had a headache...I told them, but they could not help me. There was no doctor's prescription [for injection], so there was no injection for me. I must be patient. Nothing would happen even if I screamed. It was useless, and would make doctors more tired.....

Fe2Pa630-636/16

Sri, a 44-year-old female who had developed complicated disease of tuberculosis and had been admitted in a hospital. She had severe headache and wanted a doctor to check on her severe symptoms because she suspected that she had developed fungal meningitis. The nurse understood the problem, but she could not help or respond to Sri's needs because the doctor did not come to check her symptoms at nighttime. Sri expressed what terrible event she had:

I couldn't move my head. I felt like my head would explode. Even ice pad couldn't relieve the pain. I told the nurse and she kept giving me paracetamol twice. She didn't ask me how I felt after taking a pill. I asked my mom to tell the nurse when I couldn't bear the second pain. The nurse did the same thing. Until the third pain, I asked my mom to call a doctor. The nurse kept saying, 'The doctor will see you soon. Just wait!' I waited from nighttime until 10.00 a.m. and told the nurse that the doctor did not see me yet. She then called the doctor again. She told me that the doctor would come... but the doctor did not come...why?... it was terrible for me.

Fe1Pu, 1270-1277/38

Lack of experts for specific care and treatment

Most of the participants who lived near a community healthcare setting told the story of inadequate treatment and care from healthcare providers. There were inadequate specific health personnel and AIDS experts in health settings especially in emergency care. Sufferers had the experiences that healthcare providers who were not experts sometimes avoided taking into account complications of the disease and lacked skill to diagnose the complication of drug reaction. These could lead to a cause of severe complication and death. A participant who had Steven Johnson's syndrome expressed her suffering experience from the side effects of drugs. She felt alienated by the health providers' action:

I took a wrong drug because I thought that it was a painkiller. I got rashes all over my body. The doctor [nurse] did not care or give any treatment. She only looked and told me it was nothing wrong. She might think that I was infected and this was no need to care for me. I was sad. After I saw a doctor [nurse] at

the emergency room, I fell ill at home. I could not walk. I thought that I might die at home. My household's members told another doctor [nurse], and she came to visit me at home. The doctor said that I might be allergic to something. My dad took me to the hospital. I was allergic to drugs (Sulfa). It was very painful. I felt sore on my body and deep into my bones... The doctor [nurse] didn't know the cause either. She did not care or concern about me (in tears).

Fe 1SuK 32-34 /1, 40-43/ 2

Samorn, a 35-year-old female who was prescribed with a drug to prevent opportunistic infection and she felt discomfort after taking the medicine. Her husband had to take her to the emergency room every night. The general doctor who worked on a night shift did not concern about drug reaction. She was depressed and worried about spending a lot of money to go to the hospital each time but had never been admitted for further treatment. After she had suffered from having to be on medication for three months, she was admitted by experts because of drug reactions. Samorn expressed the suffering she had when receiving care by an unqualified doctor:

It was so difficult to stay in hospital. Unless it was necessary, we had no right to stay. Almost AIDS patients were forced to go back. When I had sulfa allergy, I was so downhearted. I felt very dejected. The reason why I wanted to stay in the hospital was not a need to stay comfortable but I felt that there was no one-day for me to feel the comfort. It was always hot and fiery in my body. I also felt liable to vomit like there was a fire burning in my body. Every day I got a countless fever. However, [general] doctors told me that it was nothing wrong and always let me go back. I had a treatment in few minutes but spent more than 1,000 Baht to cover the medication each night. It always happened like this, so I became despaired... After I had a treatment at the OPD, I finally knew I had severe sulfa allergy and the doctor professor admitted me in hospital. ER doctors let me be tortured by sulfa drug for 3 months!

Fe5B, 1696-1702/ 48

There are healthcare services for outreach patients that are not adequate and have no quality because the prisoners could not receive basic or symptomatic treatment and cares. The lack of healthcare providers' knowledge, expertise, and equipment could cause severe complications and increase death rate of patients with

AIDS. Noi, a 23-year-old woman living with AIDS and pneumonia (PCP), shared her experience when she was in prison. Noi described a terrifying story about people who were neglected of care like this:

Saijai was sick like me. She couldn't eat. Her neck was stiff like this (showing where Saijai had a stiff neck). She wrote to me 'Please tell the doctor [nurse] that I couldn't eat.' But the doctor didn't help her. She was very sad. She had an opportunistic disease like me, so she should have been sent to the hospital. It would be better than to let her wait for death. Namphon, however, faced the same event. She was very tired. She was suffering before being dead. The doctor [nurse] could not do anything. She let the patients die. There was no oxygen tank. There was one or two patients who died daily in this prison. I had pity for them. If they died peacefully, it would be okay. But it was not like that!

Fe6Ra,146-148, 156-167/15

Being interned in life threatening services

In general, persons with HIV/AIDS were isolated from patients with other diseases in the same area of healthcare unit when receiving care at hospitals. Most of the participants expressed their sad feelings when they were put in the unsafe care. For this reason, they were vulnerable to be infected with other opportunistic diseases like tuberculosis. They explained that there was less infection control and prevention for patients with HIV/AIDS from being infected with opportunistic infection at healthcare settings.

A participant, Pen, perceived that her husband had tuberculosis infection when receiving care at an emergency room. She regretted the negligent care and being interned in life threatening services:

My husband died sooner than he should have because he stayed next to a TB patient. ...He had never been in a hospital, and he stayed in an emergency room. There were many patients with TB infection there. My husband was not TB infected. He got it when he stayed next to a patient with TB in the emergency room. It was an air-conditioned room, and the air didn't ventilate well. The infection had no where to go. It was just around there...I didn't want my husband to stay near the TB patient because it was easy to get this opportunistic disease and become complicated opportunistic disease. They [doctors] should have considered that those infected persons [living with

HIV/AIDS] were human beings. We were not animals. They should have looked at the patients as their relatives, not as persons waiting to die. That was wrong.

Fe2B, 663-669 /19

A female participant with PCP described an unsafe healthcare unit where treatment was provided for HIV infected patients with opportunistic infection. The inadequate infection control might cause persons with HIV to have symptomatic AIDS easily:

The medical clinic was very crowded and it made me feel uncomfortable breathing. If I were not sick, I would not come to this clinic. The air was not well ventilated. The clinic was compressed in one small room with every infection disease. I thought my immune was very bad and could be infected with many diseases like TB because I had to stay with many infected patients for many hours. Really, lots of germs were collected in that room. I had pneumonia because I was infected from this room.

Fe5B, 329-332/10

There is no legal abortion service for pregnant women in government hospitals. Participants with AIDS infection shared the experiences of illegal abortions at private clinics, since healthcare providers could not provide legal abortion for them. A 35-year-old female who already had one child and had economic problem and did not want another child explained that she was pushed to use unsafe abortion service. She described the torturous experience she had:

The doctor could not do abortion for me, so I decided to go to Chaing Rai to look for the clinic [illegal abortion]. It was crowded...The staff spoke less. He told me to come here for a week later with the money. I went there in the following week. ...The doctor did abortion by sucking [via vagina] without giving me an anesthetic. He gave me some antibiotic drugs and painkillers. I got cramp in my abdomen. It was very painful. It was hurt more than delivering a baby. I bled till I went back home.... It was very dangerous.... I was afraid of dying also but I had to do this. It cost 1,900 Baht. It was very expensive!

Fe5Pa, 93-103/5

Constraints of treatment and care

The participants narrated the struggling experiences in utilizing special treatment and services for patients with HIV/AIDS in provincial hospitals located at centers. Patients with HIV/AIDS received only symptomatic care in community hospitals and general hospitals. If they would like to receive anti-retroviral therapy or special investigation, they tried to seek healthcare services by themselves. Most of the participants who stayed in suburban areas tried to go to receive specific care at provincial hospitals. They described treatment and care which involved a long wait, case selection for treatment, and limitation of continuous treatment.

Waiting for a long time for ineffective treatment

Provincial hospitals, and general clinics, did not provide prompt services nor special examination in details. Participants were dissatisfied with the care services at these hospitals because they were crowded and lacked special treatment from healthcare providers. A participant, Khum, described with disappointment and gave reasons of the patients who were denied an early treatment from provincial hospitals:

Going to provincial hospital is not very common for people in a rural area. We have to wait till we cannot bear the severe sickness. So, we go to the hospital. ... When we arrived at the hospital, we didn't get the service right the way. We had to wait for half a day...like this. When it was our turn, the doctor spent less than 5 minutes to check on the patients. I was not satisfied. I waited for a long time and got 10-20 pills like those I used to get from a public health center near my house. I wondered what they were doing...I had to wait for so long a time. My illness could not be cured at the public health center. That was why a nurse told me to go the hospital. I received the same pills twice when coming here. I had pills to relieve my stomach discomfort. The doctor did not check me in details.

M3Su, 589-601/19

A female participant described the healthcare services in a university hospital where her husband and she had gone to follow-ups every month. She expressed the provision that lacked convenience and took too long a time:

I have to go to hospital early in the morning because I am afraid of traffic jam. I have never met the doctor before 10 a.m. I always meet the doctor around 11 a.m. If my husband had to receive blood transfusion, I had to go back home at 10 p.m. My husband had to wait for the reserved blood group and stayed at emergency room at least 3 hours. If he received blood transfusion for 2 packs, it used 6 hours for treatment. I had to phone my daughter who stayed home alone and told her to find something to eat. We sometimes went back home very early around 3 p.m. if we did not have special treatment at emergency room.

Fe5B, 323-327/10

Routine service access with no quality HIV/AIDS service

The arrangement of specific AIDS treatment at general hospitals was limited for several clients with HIV/AIDS who came to utilize healthcare services because the HIV clinic was opened only one day a week. These caused the inconvenience and raised travel expenses for patients. Thus, persons with HIV/AIDS had obtained the ineffective service. In the crowded services, with constraints in environment, patients did not have opportunity to consult with doctors adequately and appropriately. A participant who had to travel from rural areas to a provincial hospital every month commented on quality of service as follows:

This nurse in community hospital suggested I go there. So, I went there on the first Thursday of the month, right? After the registration, I had training. In the afternoon, wasn't it? I had just seen the doctor. He gave me drugs following my symptom description. Doctors never asked me, but they just saw my symptoms and gave medicines to bring back home...not good...because he never asked me in details. Lots of clients, right? 200 – 300 persons...it might waste time to ask each person. I had waited till the doctor arrived at 2 p.m. You see? 200 – 300 patients waiting for him...I had to share the bus expense with the others. We had to hire it in order to go from Prasat District (Surin) to our village. Nowadays it costs me at least 100 Baht without meal. If including meal and bringing a child together, the cheapest rate is 200 Baht. Each time I see the doctor, I rarely talk to him. Sometimes he just asks me only 1 or 2 questions and signs a prescription. That's all! In my opinion, I think it doesn't work..

Fe3Su, 207-211/6, 215-220/7

A participant who lived in another district far from a provincial hospital described the routine services for patients with HIV/AIDS at the out-patient department. She suggested that adequate doctors provide treatment and care in special clinics:

The treatments provided by doctors at this provincial hospital were available only in the afternoon. It took a long time to wait for the doctors. I live in Choompon District. I have to spend more than 100 Baht on the bus ticket. I have to wait for the doctor until 4 p.m. -5 p.m. to receive treatment. Sometimes we miss the public buses to go back home.... We have to wait for the doctor in the morning like this but no doctors come in the morning.... Some patients had severe illness, but they did not receive any treatment immediately. They cried from pain, but no one in this clinic could provide treatment for them. We have to wait for doctors to check the symptoms and then admit or transfer the patients to emergency room.... It is very terrible. We need more doctors to treat us.

Fe3Su, 239-242/7, 243-250/8

Most participants who lived in rural areas where there was a public healthcare scheme or a 30-Baht card were not satisfied with health services at designated hospitals. They faced with the routine services that did not serve their specific health problems. Some participants never had health check-up nor received the prophylaxis drugs to prevent opportunistic infection. A female participant with PCP discussed the unqualified health services that made her lose follow-up and seek other healthcare services:

The doctor asked why I was there, and I told him that I was HIV infected.... Since I had delivered my baby in 1999. Now I was very tired and had chest pain. He told me to leave the room, have blood test, and come for the follow up next month. I wondered why he didn't listen to my lungs. Why didn't he check on me? He didn't even look at me, but he kept on writing. I asked if he would check or give me some treatment. He replied 'You are doing well.' I said, 'I am not fine, and I am very tired, so I am here.' I cried inside and was very angry with him.... While I was talking to him, I was very tired... He did not respond and I did not have any blood test...I hoped that I would have received some drugs, but I got nothing....I had not seen him afterwards...I went to other hospitals, and the doctors gave me Sulfa to prevent PCP. Although I have a 30-baht card at this hospital I don't use it because I am afraid to meet that doctor.

Fe4Ra, 335-336/10, 334-351/11

In addition, the perspectives of healthcare providers at community health settings were congruent with participants' perceptions in terms of the inadequate staff and ineffective services, as a nurse who provided care for patients with HIV/AIDS described:

There is only one doctor in this hospital. We have problems when AIDS patients come to the hospital and do not meet the doctor. We have to treat them like doctors. We have to treat them while we don't have any treatment skill or knowledge. Everyday we can give them only routine care. We don't have the drugs for some patients who have severe sickness like fungal meningitis. We can provide them with I.V. drip of Amphotericin B. but we don't have Fluconazole for them. We have limitation of budgets for essential drugs also.

N1, field note 1/12

Unable to access care service, and caregiving becoming relatives' duty

Participants who were caregivers and care receivers shared their experience of the reason to provide care to their HIV/AIDS relatives at a hospital. Since the number of health providers was insufficient compared to the number of patients, the burden fell on elder relatives, a wife, or a mother of the HIV/AIDS patients. The caregivers were very frustrated to take this role. Less rest and more stress made the caregivers ill. Some of them lost their income, as they quit their job to take care of their loved ones.

Malee, 36 years old, took care of her husband who had fungal meningitis and got stressed because she did not receive support from healthcare providers. She felt desperate and became ill because of the burden. The serious experience of caregiving was reflected as follows:

Nurses don't closely take care of [AIDS] patients here [ward]. All cares are up to cousins. It's a duty of cousins to help their own patient. However, almost all patients didn't cause any trouble. But for me, he [husband] asked for help every night.... He couldn't walk or stand...so I always had to help him, to give him a hand. I preferred staying here because I wanted to watch over my husband and his symptoms. Each nurse had a lot of work. If there were 20 nurses per day, surely there was no need for cousins' hands because they could help each other to look after patients, right? In fact, there were only 3 or 4 nurses while there were 30 or 40 clients...impossible to deal with, right? We must understand this point. It was overloaded duty for me too. Here this one,

there that one, lots of trouble...I had no time to rest. I had to look after my husband days and nights. My arms and back were aching. Nobody helped me carry him. Sometimes I felt so depressed. I had got a deadly headache.....

Fe3Su, 482-485/14

Sri expressed her emotional stress when her mothers who took care of her at the hospital could not serve her needs or solve her problems. She had severe pain and side effects of anti-fungal intravenous drips, and few staff went to visit her or ask about her problems:

While I was taking Ampho, there was some side effects. I felt very cold and chilled. I had body pain. It was terrible! I didn't want any part of my body slip from a blanket. I had to be patient because I knew this was the side effects of drug. But I didn't want to depend on my mom. She was old and could not respond to everything well. When I was in a severely bad mood, I was very self-centered and said something hurtful to my mom. I sympathized my mom. There were only my mom and I who were confronted with such problems. Healthcare staff didn't come to give me any care. Humm...What could I do to be better? I rarely have seen the health staff visit me each day.

Fe1Phu, 1226-1233 / 37

Sayjai, a 25-year-old mother with HIV took care of her AIDS child for a long time at the hospital. She told how it had an impact on her work when she performed her role as a caregiver:

I lost my son when he was 4 years and 6 months old. Last year, he was very weak throughout the whole year. He was back and forth to the hospital every week. I was very depressed and worried about him. I lost weight because I could not eat, and I had less rest. When he was admitted at the hospital, I had to take care of him by myself because there was inadequate staff at the children's ward. If I left him alone, no one could take care of him at the ward. I had to take a leave often to take care of my son. I finally quit the job to take care of my son when he was very sick....At that time, I was very distressed....

Fe3Phu, 119-121, 123-125 / 4

Case selection for anti-retroviral projects

There were governmental anti-retroviral projects which provided free anti-retroviral medicines for 10-20 patients at specific clinics in provincial and university hospitals. However, the projects could not afford anti-retroviral medicine for all

patients with HIV/AIDS. Thus, few persons with HIV/AIDS who had suitable immunity and deemed qualified were selected for anti-retroviral project. Several participants claimed that they could not have access to the equality of anti-retroviral treatment. The participants who were not selected told the negative consequences on their health due to lack of the opportunity to access anti-retroviral therapy:

A male participant with TB infection said he had developed poor health and had opportunistic infection because he was not selected into the anti-retroviral projects. He told how disappointed he was of the treatment he received:

I'd like the doctors to give me better medicine, not an ordinary Paracetamol. ... They should give me anti-viral drug in order to prevent any worse symptoms. I'd like to take it so that I could walk by myself.... Clients don't know what drug they've got. Only the doctors know what kind of drug they have given. I noticed they had given just a normal pain-relief and cough syrup. Please...give us better medicine and better suggestion. Not at all. I have seen some AIDS patients who were once getting worse. Their body was full of pimples. Now they become better while I'm getting worse because I do not receive anti-viral drug...It was worse...The same HIV infection but different treatment....

M1B, 870-879/24

Poj, a member of the HIV/AIDS club, expressed his feeling toward inequity in access to effective anti-retroviral therapy. He compared himself with other volunteers who were selected into the quality anti-retroviral therapy project. He expressed the different quality of anti-retroviral drugs among persons with HIV/AIDS that made them fall sick and be dismissed from work:

I asked what drugs he [AIDS volunteer] took, he didn't tell me. The anti-viral drug he had was different from mine. But he said the project has not enough budgets for all HIV patients. I had taken 2 types of anti-viral drugs but I could not continue to take them because I was dismissed from work and had no money to buy drugs. I stopped taking them. The government should help people with HIV infection by monitoring the quality of drugs. The good anti-viral drugs should be distributed to more patients. The government should also make it easy to get the drug. It must be available in any hospitals. I hope the government will take the action seriously, and no longer neglect people with

AIDS. If they had included me, I would be healthy and I can work. We will be happy to live, and not to rely someone much.

MM1B, 791-799/ 22

Thong told the story of the unequal treatments that the persons with HIV/AIDS received from different healthcare services in the same hospital. He did not receive anti-retroviral treatment because he was not referred to a special clinic after he recovered from complications with lymph nodes related to tuberculosis:

As far as I know, the patients who the doctor refers to the 3rd floor [of Immune Clinic] would receive anti-retroviral drugs without saying a word. There are specialists on that floor for the AIDS project. For other floors, there are general care and treatment. Well, a patient can request for anti-viral drugs, and that must depend on whether the patient has money or not. I was treated there for 5-6 years, and the doctor never gave me the anti-viral drugs. He treated me according to my symptoms. He never checked my CD4 until I requested. I felt discouraged. Doctors who treat me should improve their ethics in health profession. Doctors should know what is the better treatment, then they should give the quality drugs to patients. Why cannot the doctors in others be qualified like those working on the third floor? They are all the same professionals, aren't they?.....

M2B, 404-412 / 12

Persons with HIV/AIDS who are drug addicts cannot approach other treatments of HIV/AIDS because they are excluded from the anti-retroviral project. A 33-year-old participant with HIV/AIDS received only the treatment from drug addition clinic. He did not monitor his immunity or receive any treatment when he had symptoms related to AIDS. Yo described the services he had received:

I decided to quit Heroin because I sympathized my mom who was getting old...I am now addicted to Methadone instead of Heroin. Without Methadone, I cannot concentrate. I will be very moody.... I didn't see a doctor give me any treatment on AIDS...He never refers me to the treatment even though there is AIDS clinic in this hospital. I am not on any drugs [anti-retroviral drugs]. I am worried about my health very much, and I have no idea what stage [AIDS] I am at. I am very fatigued, I lose my appetite, and I have fungus on my tongue. I lose my weight and I sleep less. The doctor gave me more sleeping pills. He didn't check on AIDS or give any drug to relieve my illness.....

M1B, 112-116/ 5

The discontinuity of AIDS treatment

The limitation of anti-retroviral project, particularly given for only one-year, made participants worried about the access to continuous drug treatment. The participants who have received anti-retroviral drugs during pregnancy did not receive continuous anti-retroviral therapy after delivery. In addition, many anti-retroviral projects were not run successfully because few patients were left. Several participants who did not have continuous anti-retroviral therapy had chronic illness and developed AIDS symptoms.

Nok, a participant with HIV/AIDS, described the discontinuity and the inability to access data to make decision on drug introduction. She missed a chance to join the new drug project. She was also worried that she might be sick again:

There are only 8 of 24 [clients who joined the project] left. ...Some died while some stopped the drug treatment because they couldn't take drugs anymore. ...At that time, I didn't know about anti-AIDS drug. ...I just joined Day Care. Moreover, they didn't tell me about AIDS drug's effect. Now I can bear it and have more knowledge, so I want to advise other patients. There is no need to take anti-viral drugs unless necessary. I've read from books and learned from drug experts. They said that AIDS drug is suitable for symptomatic patients. If you have no such symptom, it will make you worsen quickly. Especially when the drug project is run only for one year, right? You will become sick very fast or suffer from drug resistance if you stop it. I'm so anxious, too. What'll happen after the AIDS drug project is finished?

Fe2Pa, 453-460/11

Chard, a 45-year-old participant, described the useless one-year anti-retroviral project in the provincial hospital. After the project was finished, he developed AIDS symptoms and could not have an opportunity to apply for another anti-retroviral project:

It was very risky to enter anti-viral project in a hospital because an HIV infected person can receive anti-viral drugs for only a year. They don't provide drug for us continuously. It was a waste of budgets. For me, I tried my best to take drug. After the project finished, I got worse. My immunity dropped. It was

a useless project for us. I also could not apply for the new project because they selected new HIV patients who had never taken any AIDS drugs.

M3Phu, 329-338/10

Prateep, 26 years old, was formerly in the anti-retroviral therapy project and had drug resistance. He had poor health because he could not continue anti-retroviral therapy from several government hospitals. He was frustrated with the unsuccessful approach:

I thought I tried my best. I spent a lot of time going to the hospital. I spent a lot of money for transportation that was not comfortable. At that time I did have not income. When I went some where, I had to ask for money from my relatives. It caused them trouble. I was not their problem any more. Why? I expected help from hospital services, but they could not help me. No offering for us to contact them. I had no way to go. I did not know what to do. Siriraj [hospital] rejected me, Chula [hospital] rejected me because I had the history of Anti-viral drug use. There is no project for us, so I do not take any drug... I feel hopeless.

M21B, 419-424/ 12

A female, 35-year-old participant, had received anti-retroviral therapy during pregnancy. She did not receive continuous anti-retroviral medicines after she had delivered her baby, so she developed chronic illness with PCP. She expressed her condition depressively:

After I had my baby they [doctors] didn't tell me anything about my baby and myself. They did not tell me about the anti-viral drugs.... Why they gave me the drugs and they brought the drugs back after I had my baby. They did not follow up on my baby and me anymore. I was worried about my baby's blood test. They did not give anti-viral drugs to me any more. Now I got pneumonia and the doctor gave me only Bactrim.

Fe5Phu, 735-738 /23

Unmet support from social welfare services

The participants who lived in Bangkok and big cities did not get a social security card and had to pay for the treatment by themselves, especially those who were not the anti-retroviral therapy project's members. Thus, participants had

economic problems trying to afford the expenses. Some participants did not receive any advice about financial support from social welfare services in the hospital. However, some mobile participants and those who did not have health welfare received a discount on drug expense. They were ashamed to ask for support and felt they lost self-respect and dignity.

A participant described the financial support she received from social welfare officers:

They should consider supporting us by reducing the price case by case. They should collect those who have income half of the drugs fee, without many discounts. Persons with AIDS who can apply for anti-viral project are healthy infected workers. They've got it free of charge while we earn nothing but have to pay more than half the price. They charged us through our bone. When we asked for discount drug expense, they insultingly looked at us as if I was a beggar. I'm so ashamed.

Fe22B, 217-219/6-7

The participant who did not have public health welfare said that she felt sorry about her economic problem that made her have low self-esteem when asking for help from the fund of social welfare in the hospital:

...It was so difficult to contact social workers if the doctors did not refer patients to consult them. When I met them, I had to make them pity me. I know I felt upset and cried all the time. I sympathized myself and felt so tired. When I talked to them, I thought it was not so easy. They knew that I had no job and I was poor because nobody wanted to employ AIDS infected persons...They talked with me modestly. In my opinion, it's not so easy to receive free medications from social workers. If I had enough money, I would pay by myself....I don't want them to look down on me as a pauper...

Fe5B, 602-607/ 17

Porn, a symptomatic AIDS patient with TB, expressed her suffering when asking for help from hospital's social welfare department. She perceived that the poor HIV/AIDS patients did not receive needed support:

...So suffering that I sometimes cried. When I asked them, my first time, for welfare aid, they asked me 'Didn't you have any money?'...They said they

would change the drugs, so I asked, 'Change drugs? Will I get well if the drug is changed?'...Do I have to change drugs if asking for social worker aid? They replied that the drug was expensive. For social welfare receivers, they had to give the inexpensive drugs. I agreed but I thought they did not select the good drugs for me. Yes, I'm poor. I have no choice. I have no money but I need drugs. Though doctors change the drugs, I have to accept that. I think like this since my first asking. If I had money, I'd certainly never ask for their help. They treat me as if I am a beggar...

Fe8aB, 1293-1298/ 37

Sub-standard healthcare environments

The sub-standard healthcare environments including lack of qualified resources and service management are the factors that hinder persons with HIV/AIDS from accessing quality and continuity of care. Thus, sufferers with HIV/AIDS have both difficulties in accessing and receiving care at health institutions. Moreover, they are facing many barriers related to healthcare access such as unqualified drugs, lack of information of care and treatment, unscientific alternative therapy, ineffective referral system, and limited and discontinuous resources management. Participants told their stories as follows:

Receiving unqualified drugs

Participants who had children with symptomatic AIDS described the quality of the drugs they received from healthcare systems. Although some children with AIDS received the support of anti-retroviral therapy project, they received the expired medicine. Participants who were AIDS volunteers expressed the unqualified medicine for AIDS patients:

A lot of children with AIDS in my village did not receive anti-viral drugs. Few of them could receive drugs but I think it was not useful because they were at the end stage of AIDS and were very weak. I have also seen the AZT syrup they took was an expired drug. Why did doctors give the expired drugs to us? Although they said we could take them about 3 months after its expiration date.

I did not want it for my children. Why didn't they give AZT to us early on before the drug was expired....

Pa2Fe2, 335-362/10

The situation that participants expressed was paralleled with healthcare providers' explanation:

We have the problem with the anti-retroviral drug projects because we are afraid that the project is not continuous. The patients also hope for the long run project from the government. If they could not gain access, they think it is up to their retribution. Sometimes, we could not withdraw the drugs on time because they were sent from Bangkok. Sometimes we received the drugs that were nearly expired.

N2 Field Note 2/12

Being left to utilize unscientific alternative therapy

Most of the participants who had their illness symptom present were excluded from the anti-retroviral project. Owing to expensive anti-retroviral drugs and the fact that health welfare did not cover it, persons with HIV/AIDS attempted to seek for the better and inexpensive medicine outside health settings themselves. Participants described their suffering experience when they went to receive herbal drugs at an illegal clinic far from their hometown. This herbal drug was advertised that it could heal AIDS, but its quality was not approved by the government. Sufferers expressed how difficult and costly seeking for alternative care was:

I always took care of my husband and took him with me to be admitted in the hospital and discharged from the hospital for many times during 3 years. He did not receive anti-viral drugs....I wanted him to get better. My husband had never worked because I worked and earned money to provide care for him. When I knew what drugs in what places were good, I tried to seek them for him but he did not get any better. When I heard that the drug from Ban Bangpakong was good and some clients could be cured, I spent a lot of money to travel from Surin. I went there to stand on the line of 1,500 people to receive the drug for him...It was terrible....He did not get better...I had spent a lot of money for this treatment...

Fe6Su, 796-802 /22

Participants had to make decision to utilize alternative medicine due to its inexpensive cost. The doctors suggested that they take anti-retroviral medicine because they had low immunity. However, they did not have money to buy anti-retroviral drugs, so they received only symptomatic treatment. Thus, they decided to take alternative medicine because it was the last choice for them to receive treatment.

Samorn, described the struggling experience when trying to access the alternative medicine that the government let the patients use:

I went to Bangpakong Clinic alone to get V-1 Immunitor. I got 28 tabs because I could pay for 500 baht. After I finished these tabs, I went there 5 to 6 times to continue my treatment. I went there by bus with my daughter. We left at seven in the morning. There were about a thousand people lining up for the drugs. Some clients came from the north. I have seen the very sick patients. I thought they did not receive care at hospitals. If patients have less money, they receive a few medicines....I decided to use V-1 because it was the last choice. My husband and I did not get better from V-1. Many AIDS patients go to that clinic because hospitals did not give them anti-viral medicines. I don't know why the government lets patients take these unapproved drugs. If the government provided anti-viral drugs to the patients, they would not suffer like me.

Fe5B, 667-668/ 19,695-698/ 20

Inadequate healthcare services to prevent secondary infection

Thirty-eight participants had been symptomatically treated but had poor health. Half of the participants had never been treated by anti-retroviral therapy. They did not have a CD4+cell count test information and had never been monitored for immunity. Every kind of health security card did not include this expense and CD4+ cell count testing was not offered in government healthcare settings e.g. Phuket and Rayong Hospitals. Many participants never had routine health check-up after being informed of their HIV infection. They also never had CD4+ cell count test or received the details about self-care or prevention of complicated infection. Some participants were

not informed of further information of self-care and self-monitoring. The healthcare services obviously lacked health promotion and disease prevention.

Sri, 44 years old, had TB infection. She told the story that she did not receive health information to prevent the disease when she was healthy:

At that time my CD4+ was still high. I think I could remember it was about 540. So, I could not take the drug because my immunity was too high. I should have CD4+ lower than this so that I could take the drugs. So, I did not take any anti-retroviral drugs. Afterward, I did not have any health information or contact with the hospital for further treatment. They did not advise me to have chest x-ray or health check-up.... Not more than three months, I got sick and admitted in the hospital. It was very fast to get sick. I was very tired and had difficulty breathing...The nurses were also stumped by my symptoms. I was also sad why they did not take care of me earlier. When I was not sick, they should have given any advice to me...but not at all...

Fe1Phu, 146-151,154- 159/ 6

Nob had been HIV infected for ten years and got worse due to TB because he had never received the information of TB prevention or routine health check-up. Although his wife had TB, healthcare providers had never advised them on how to prevent TB infection at home. He expressed how he was denied treatment after his wife died and he was hopeless of his illness:

I went to follow up at the hospital every 3 month with my wife. I have never lost follow up. Recently, I lost follow up more than 3 months. I don't want to go to the hospital because my wife has passed away. I do not have any willpower to receive any treatment. I ignore myself, and let it happen, so I get worse. Before my wife died, we went to the hospital together, every follow up. I have never had an x-ray for TB. Doctors never checked my health. I was busy about taking care of my wife so I got TB from her. I never went to the hospital that time. I went to the hospital when I had serious illness. Now, I had much coughing and became thinner...and weakened.

M11B, 95-99/ 6, 318-320 / 9

Samorm, 35 years old, had AIDS symptomatic with PCP. She told about healthcare information that she did not receive from healthcare providers when she went to the hospital every month:

Since I started my treatment at this hospital, I have never received any health information. The doctors did not tell me about prevention of complications of the disease. The doctors focused on only treatment of the disease. They had not advised me on how to prevent complication of AIDS. So, I did not have any self-awareness or care about myself.... I slept late and worked hard, so I had pneumonia. If the doctors had advised me on how to take care of myself, how to eat useful food, or given the anti-viral drugs to me earlier, I would not have had complications like this.

Fe5B, 1975-1980/56

The young female participants informed that they never had pre-marital blood test. Male participants stated that they had never used condoms to prevent HIV infection when they visited sex workers. Therefore, females were at risk of HIV infection by sexual transmission between husband and wife. Although pregnant women have received anti-retroviral therapy in order to prevent HIV transmission from the mother to the baby, they did not receive the health information to prevent secondary infection. Furthermore, they did not receive suitable information to decide for family planning. Most female participants did not receive advice about condom use from health service either.

A participant, Malai, told this story of lack of information of condom use to prevent HIV infection and for family planning:

I had the second baby because I had no money to buy birth-control pills. The doctor told me that but I had no money. I also didn't know about condom use. Nobody in clinics taught me or gave condoms to me. I didn't know and thought that my husband may know what condom was, but not at all. He was AIDS infected but never told me before we got married. Just keep it a secret. I knew later that he was infected before he met me.

Fe5Su, 260-271/ 8

A participant who was an AIDS volunteer told about family planning services that did not facilitate females with HIV/AIDS to access secondary prevention. Most of them could not access the information of condom use:

All couples with AIDS did not know how to use condoms to prevent AIDS. They all knew that they had HIV infection but they did not prevent it when they had sex because they did not know it. They said healthcare providers did not advise them on how to use condoms to prevent infection. They only advised about hormone implant to prevent pregnancy. After they delivered the baby, they said they had never used condoms...The clinic also had not enough condom supply for them because they received only 8 condoms per months.... The young females with AIDS, 15-16 years old, said they were not enough for them....and they did not have enough money to buy condoms.....

RaFe4, 529-532/16

Prinya was a hot-line consultant. He said that the asymptomatic HIV-infected patients were worried about their health problems all the time and they lacked consultants. Some HIV-infected persons were afraid of having to disclose themselves, so they were afraid of going to the hospital. At present, there is also no special health service for persons with asymptomatic HIV/AIDS:

In fact doctors should give advice about self-protection and self-observation and that patients should see doctors as fast as they can. If something changes, they should not just stay calm and wait till it can't be cured. Almost all doctors let patients go back and give vitamin without any suggestion. People with HIV infection called me and told me that they did not understand why they were forced to go back. OK, there were lots of patients but doctors should give some services.. Like self-preservation suggestion or consultation.....They were worried too much...Especially when they've just been sick. Only red pimples appeared, they panicked and wanted to cry...they asked me why they had pimples. When I saw them, it was just a small pimple or an insect bite. ...

M2B, 619-621, 622-633/ 18

Inappropriate healthcare information to promote drug adherence

Some participants who were in the stage of opportunistic infection did not have any information or were not closely monitored for drug adherence. Many participants who were treated for tuberculosis for more than one year had developed multi-drug resistant strains of TB. They claimed that they did not receive treatment information clearly when they had first the illness. They received information of treatment from their friends and HIV clubs after they suffered with chronic diseases.

A 22-year-old female participant who had TB infection for more than one year described having no information about TB drugs from healthcare providers. Thus, she was despaired and discontinued drugs. When she got the TB drug information from the HIV club, she expressed regretfully of former services:

I don't know... The doctor didn't tell me that TB germs could resist the drugs. My friends only told me that I had to start taking it again if I forgot. I sometimes took drugs and sometimes I ignored it... So I had to start taking it again and again. Doctors never explained that TB in my lungs would resist the drugs and make me take drugs in a high dose... I don't like to take drugs, so I stopped taking it by myself. The more I took, the more I was tired. It's boring....

Fe6Ra, 314-319/10

Sarapee, a 26-year-old female, told the suffering story of being taken out of the anti-retroviral therapy project at a government hospital because she had TB infection. She felt disappointed of not being informed about how to prevent opportunistic infections such as TB. Physicians discouraged her about the prognosis of the disease. She expressed her distress:

I was treated and received anti-viral drugs from the hospital in Bangkok. Doctors gave AZT and Hivid to me. Then I have got TB, and the doctor said to me frankly, 'you are at the third stage of AIDS. I don't have the drugs to treat you.' When I took AZT and Hivid, I also had drugs' side effects. At first, I felt very tired but I could tolerate them. I had checked CD4+ cell every eight months. Finally, I had drug resistance. CD4+ decreased. Doctor never told me about how to prevent TB. I had never known that I could have TB if I did not take care of myself. When I have got TB, he excluded me from the project and I was very depressed.

Fe6 Suk, 118-133 / 4

The overwhelming information of anti-retroviral drugs' side effect was a factor that made participants who had taken drugs for a while worried about the treatment. They were also anxious about the drug resistance that could make them change the kinds of drugs and lose expenses or force them to resign from the anti-retroviral drugs

project. Some patients felt scared of drugs and discontinued taking anti-retroviral drugs when side effects of them appeared. One participant stated that:

I've received the anti viral drugs till now. It is like I have been bullied. The doctor said, 'you'll get rashes on the skin or inflamed liver after taking this drug.' That sounds frightening. I myself don't want to take drugs so I'm not sure whether that was a suggestion or something else. For the first 3 drugs I've taken, I asked the doctor about the side effects but he couldn't tell me.... After I had changed to the 2 new drugs, I got a rash and inflamed liver. Sometimes my eyes were swollen, so I had to stop and hurriedly see the doctor. I'm afraid that I would die from drugs. Now I take drugs with a risk. I'm scared that the rash would appear again...so I stopped what I had taken.....

Fe5B, 424-431/14

No continuity or referral care networking

As the counseling service was provided only individually and confidentiality of clients was guaranteed, it could cause secondary infection to the client's spouses. Participants who were wives reflected the risk of HIV transmission from husbands who kept their status on HIV/AIDS a secret and put their wife in jeopardy. Instead of reaching to the healthcare and treatment at the beginning of the wives' illness, they had delayed treatment because they did not know that their husbands were sick because of AIDS. Women became more vulnerable to HIV infection because the counseling service lacked continuous care and concern about the patients' family.

Lunthom, a 34-year-old widowed with a seven-year-old child, was infected and progressed to AIDS. She knew she had AIDS symptoms since her husband died because of AIDS from healthcare providers. She was angry that her husband concealed it from her for 6 years. She expressed about the unfair counseling service:

The doctor should have informed me through my husband's address. I don't know why the doctors have to keep this information a secret if the patients disagree to be disclosed themselves to their spouses. That isn't fair to me. If I have known before, I would have prepared myself. I should receive any treatment early. My child is too young. By the time I knew that I was infected, I was very sick of AIDS symptoms. I had got pneumonia. I am sure that I have been infected since I lived with my husband. I must be 5-6 years. In 1996, I

was very tired and I had infection in my lungs. When I knew that I lived with AIDS, I didn't want to live....

FeSu2, 118-134/4

After utilizing counseling services, participants had a lot of trouble in seeking care because there was no effective referral care from counseling services to healthcare settings. Participants reflected a failure of a continuum of healthcare system. The anonymous clinics served the participants who visited them only by counting the numbers for surveillance but did not provide referral information and system for persons with HIV/AIDS. A participant discussed the ineffective service with no care at an anonymous clinic:

The Anonymous Clinic provides solely lab test. There is no treatment. It's like a cop arresting a bad guy. Health providers should have followed up on the case rather than let the patient confront his or her own Karma. Health providers might refer the patient to nearby hospital for continuing care and treatment.... They do let them seek care by themselves. They do not check whether the hospitals that they have mentioned could treat AIDS or not. They only said it but did not help the patients receive care.... Counting the numbers of surveillance is that all they do? That is not a continuum care and treatment!

M6B, 1016-1021 / 28

A Day Care was a service that provided care for persons living with HIV/AIDS during the daytime. Due to the limitation of bed, and lack of effective referral system, patients with AIDS had no opportunity to be admitted and cared for in the hospitals. They received treatment and care at Day Care services. Patients with symptomatic AIDS who received long treatment of anti-fungal medicine had trouble receiving continuous care because patients were getting worse from travelling. Family caregivers had burden having to spend much money and time commuting between the hospital and home.

Nok, a person with HIV/AIDS who worked as a volunteer in Day Care described the discontinuous services and the trouble the patients with HIV/AIDS and their caregivers had:

It would be better to stay here all day and night. Too bad that the hospital's beds are always occupied. Especially the patients who came for anti-fungal I.V. therapy have to come here in the morning and go back home in the evening. It's not convenient. Plus traveling back and forth makes them sicker. Some patients visited here for 15 days and some came even for a month. There is a lot of complaint about traveling from home to here. They wish they could have stayed in the hospital. The doctor always says that all beds are occupied, and says to whomever wants to stay over night that they cannot do that in the hospital, but they can in the day care. There won't be any physicians or nurses during the night to take care of AIDS patients at day care. That's why we have to go back and forth each day.

Fe2 Pa, 290-296, 300-306 / 7

Insufficient resources for caregivers and AIDS clubs

Some participants received Home Care service from NGOs because the hospital's network and the Call-On-Home project were offered only in a few areas and did not cover many patients with AIDS. In the North, it was the NGOs' duty to visit patients with AIDS's house with healthier HIV/AIDS volunteers. These volunteers told about the restriction of their efficiency in giving care to severe-stage AIDS patients who were not able to visit doctors at hospitals. Volunteers with HIV also wanted to take care of those patients and join Call-On-Home activity with formal healthcare staffs more. She said that:

Only our knowledge and experience was not enough, not a quarter of health service staff...I think if they were going to do home visit with us, everything would be better. For example, we didn't know what to do with patients who had severe pain and severe infection wound. We had to ask health staff or ask for drug, and then come back to see that patient... It should be nice if healthcare staff visited patients with volunteers at home. In some remote areas, some patients lived with their old grandpa and grandma...they couldn't come to health centers because they had no money.... They also did not know how to take care of their AIDS children too....

Fe8B, 196-198/ 17, 203-204/ 18

The budgets to run the projects were one key factor to promote persons with HIV/AIDS to access to care. For instances, the Day Care project managed by community hospital could promote them to join the activities and receive tangible support like reimbursement for transportation. Due to the inadequate and discontinuous support from the government, the project could not be run leading to reduced number of patients with HIV/AIDS who received appropriate services.

A participant, Prae, described her experience of Day Care service in community hospital that the number of persons with HIV/AIDS who came to receive the service was decreasing because the budgets used to run the projects were cut off. Thus, some participants who used to have reimbursement for traveling could not come because they had not enough money for transportation:

Now...there are about 20-30 clients... In the previous time, there were about 50-60 and they died then. Some didn't come again because of financial problem. We used to plan so many projects to earn our club and ourselves but we can't follow any plans. The other members may feel that it was a waste of time so they didn't join the group activity or things like that. There used to be a traveling expense support, about 100 Baht. Afterwards it was given only half. Now I receive 30 Baht... While those who lived in remote areas like Surin or Sangklaburi Districts said it's not enough... They had to pay bus fee 30 Baht so there was no money left for a meal... That's why they didn't want to come... Now there's no lunch offered, either.

Fe2Suk, 280-281/8, 283-295 /9

Limited and discontinuous resource management

Even though participants could find some resources in their health service settings and community, those support was not sustainable and did not cover every problem. The financial supports from the government fund were not adequate for the large number of persons with AIDS who received the grants every year. Furthermore, those who received the fund could not manage it for good profits because there was no evaluation system and safety occupational training. As a result, participants had to struggle with economic problems earning their living.

Malai, a widow who had two children, expressed how discontinuous fund management made her struggle to earn living and have health impairment:

I used to receive 6,000 Baht from citizen welfare...I think it was a useless fund. They should teach us some job training after giving the fund, so we could earn money for ourselves then. Nevertheless, they had just given money and that was it. I used to have some ducks and chickens and they all died from a disease because nobody taught me how to do it. I didn't know about animal vaccination. Nobody told me that AIDS people could also have fungus infection from poultry more easily than normal people. That was why my husband was dead from fungal infection in the brain. I just wanted to earn myself, not to ask for help like nowadays.... Now I can't call for any support because there is no aid fund provided for us...

Fe4Su,1124-1128 / 28

Participants in the north who ever received occupational training from social welfare described the discontinuous support from the government fund. There was no strategic production distribution and sales of the products for persons with HIV/AIDS. Thus, although they could work and produce a lot of products but they could not have more income because of poor marketing. Noi, a participant who had joined an occupational project, described the problem like this:

It was a very good project in the beginning. But this time it is not so good because other places also have the same product....I would like them to find the market for us....and the place where we can sell the products... The making of artificial flowers is a social welfare project.... The housewife clubs helped us to distribute the products but we did not get a good price. I heard the government policy of one product in one district does not work in my village, because there are the same products in our district and others. I would like the government to distribute our products and distribute the fund... We have no income, so it means no more money to buy good food to promote our health ... let alone taking the best drugs. We will get worse if we don't have good food to eat....

Fe51Phu, 850-860 / 18

Constraints of healthcare coverage

Most of the participants had many kinds of financing schemes such as the public healthcare scheme, social security welfare, and the civil servant medical

benefit. Participants could utilize health service only for symptomatic treatment. However, the right to all kinds of health welfare does not cover the provision of prevention of illness and health promotion for HIV/AIDS. For instance, their rights to most health welfare do not cover blood tests of immunity to monitor their health status. The health welfare also does not cover the treatment with anti-retroviral drugs. Some healthcare schemes have limitations due to the high cost of treatment and investigation as well. Thus, the poor with HIV/AIDS have to pay more for anti-retroviral therapy and investigations. Participants who had any type of health financing schemes described the constraint and inequality in healthcare coverage.

Public healthcare scheme

The public healthcare scheme or the 30-Baht gold card is the health welfare that the Thai government offers for all Thai people who do not have any health welfare. Participants could utilize each healthcare service and pay only 30 Baht. However, this welfare supports the healthcare expense for every disease except for the treatment of AIDS and chronic renal failure. Persons with HIV/AIDS described the unfair public healthcare scheme as follows:

The poor could not access to the treatment

Though participants get benefits from the public health card, they have trouble in their living because they did not have enough money to pay for 30 Baht for each service. Some participants preferred to use the former health card because they did not pay more money for treatment if they visited doctors more often. They paid for the card only 500 Baht per year and it could cover the treatment for all family members, but the public health card covered only one person. They thought the public healthcare schemes was not suitable for poor persons with HIV/AIDS:

The 30-Baht public healthcare scheme is still too expensive for persons with HIV/AIDS. If it is possible, I wish it were free. I am very poor, so 30 Baht is still too much. 30 Baht is meaningful to me. Sometime I need 10 Baht, and I don't know where to beg for it. Unlike Bangkokians, they can have 30 Baht. They might say, 'Is that all?' Anyhow, the 30-baht scheme for each visit is solely for me. It will cost another 30 Baht for my husband, another 30 for my kid. I think it's very expensive. It will cost more than 500 Baht if we are sick often.

Fe 2 Suk, 727-737/ 21, 738-743 / 22

Some participants faced the suffering in living because they must pay for anti-retroviral drugs that were costly by themselves. They cried out about the inequality in access to AIDS treatment:

30-Baht card can cure every illness...except AIDS because it's not curable. I have asked them about another sickness that is not also curable. Cancer (drug) costs more than AIDS (drug).... The government tried to disclaim their responsibility. Curing heart disease is also expensive. Each operation costs more than 1000 thousands and some even die after an operation. I'm still alive. My heart is strong, too. Why don't they cure me? The healthcare services for AIDS infected patients is unfair and unequal. They may look at us with a negative mind, so they don't care about how to cure us....

M2B, 495-500/14

One card for only one service setting limit to healthcare access

Another obstacle of utilizing a public health card is that it is not practical to all healthcare settings across the country. The 30-Baht public health card scheme requires the users to access public healthcare setting within their house registration's areas. In fact, there is mobile workforce in the country, and people migrate to work in big cities. Some of the employers do not provide social security cards due to ineffective implementation of the labor law. When these migrant employees are sick, they cannot gain access to any healthcare and treatment. That is even harder for persons living with HIV/AIDS to get an early treatment.

These following stories will reflect the loophole of the public healthcare card:

A female participant migrated to work as a sex worker in the south and had to struggle to utilize healthcare. She could not use the public healthcare card that she had from Phayao.

She had to spend much money on treatment and care causing her to be in debt.

She expressed:

I don't have any cards here...because I haven't reported to the census records office of the province to which I had moved ...I cannot use the 30-Baht gold card in this province. So, when I was admitted in the hospital, I paid all expenses by myself. Sometimes I had to pay about 400 Baht a day, sometimes 500. I should have had a health card right?...seems like another province's citizens get the unfair treatment compared with local citizens.

Fe2Phu, 37-42 / 11

Tai, a 35-year-old male from Phayao, was sick of pneumocystis carinii pneumonia (PCP). He worked at a factory in Rayong where his public healthcare card was not applicable when utilizing healthcare in Rayong Hospital. He expressed the difficulty when using health service with limited income:

I paid much on drugs, X-ray, and blood test. It was about 500-600 Baht. I paid the full cost, not discount. If it was about a grand, I could not pay for that. I had to borrow my boss' money. I had no health insurance. 30-Baht card was useless. It should allow me to use it in any place in the country. It was not worth to go back for a treatment in my hometown. I might have to pay more for traveling back and forth, and might die sooner. Actually there is a social security card that a company has to apply for its employees, but the employers do not take the responsibility. When I am sick, I pay on my own.

M5 Ra, 143-154/ 5

Participants who did not disclose themselves to their community could not gain access to health services at a hospital near their residence. They refused to use a 30-Baht gold card because they were afraid that their status would be revealed by health providers leading to rejection by community and trouble in earning their living.

Aunt Porn was a 54-year-old widow who lived in suburban Bangkok. She did not disclose her HIV status in her community because she was afraid of social

rejection. She explained the disadvantage of using the healthcare card at a hospital near her house:

I wish I could use 30-Baht card [public health card] in every hospital. It should not be limit only to the one near my house. I'm poor and have no healthcare insurance. I have no child, and my husband died. I think there should be some special healthcare card that I can use in another hospital except the hospital that is near my house. If I go there, they will know I have AIDS. It's frightening. I have many customers who come here to get their hair done. I am afraid that my customers will not come here anymore. It will ruin my income! How can I afford to pay for the anti-viral drugs then?

Fe3B, 772-773/ 21,774-779 / 22

Health welfare for state employees

Health welfare for state employees covered some anti-retroviral drugs and blood investigations. Participants who are government officers can access some old regimens of AIDS treatment. There is health welfare that is not equal for persons with HIV/AIDS. Some regimens of anti-retroviral therapy are not included in healthcare coverage because they are not on the national main list drugs, whereas treatment of other chronic disease is covered by state employee health welfare. The poor government officers cannot afford the high cost of anti-retroviral therapy. These were the following expressions of participants:

Prepaid is not affordable for government employees

A participant who was a government officer has AIDS with lymphoma and had been treated for one year. He raised his concern about his economic problem resulting from buying expensive anti-retroviral medication that state employee health welfare does not cover:

The cost of three types of anti-viral drugs is pretty much the same price as having a one dose of chemotherapy. I can reimburse on chemotherapy, but on anti-viral drugs I cannot. That is because anti-viral drugs are not in the main list for reimbursement. I pay about 17,000 bath a month for anti-viral medical cost, but I can earn only 15,000 bath a month. I pay more than I earn. Today I

can afford it because I use my savings. I am also worried about the future because I have to seek for money to cover the treatment. It's still my concern.
M6B, 520-527/ 15

Participants who were low-paid government officials explained about the suffering from expenses of treatments and daily living. A participant, Somsri, did not have enough money to spare for cost of care and treatment for her and her son every month because of her low salary. She narrated the difficulty of earning money for prepaid:

Totally, I got a salary of 7,500 per month. I paid 2,700 a month for the medicine expense, not included the future expense after my child is discharged from the hospital. I still don't know how to pay for his healthcare expenses afterwards...The doctors used to give drugs but then I had to pay myself. 3TC drug was 100 Baht a pill. He ordered 40 pills, so it cost 4,000 Baht. ...The anti-viral expense can't be drawn back. I was so discouraged. I tried to manage my income and also had to pay for treatment expenses twice a month...If my child's getting worse, we'll catch a taxi. It costs about 100 Baht. I think though you get a severe disease, if you are rich, you can still live happily...
Fe 6B, 537-550/14

Social security welfare

Participants could get health welfare benefits from the social security scheme because it provides sickness, disability, maternity and death benefits to workers. Under the medical benefit scheme, participants can select a public or a private hospital as their health providers. However, the treatment and care covers some disease except the treatment of chronic illnesses such as psychiatric patients, drug addicts, and HIV/AIDS. Participants who were workers and had social security welfare claimed the unequal of this welfare hindered access to care. Participants described the social security welfare in terms of no coverage for treatment and lack of continuous care as follows:

No coverage for AIDS treatment and lack of continuous care

Some participants were workers with a salary of 4,500 Baht per month. They became sick and paid for anti-retroviral drugs by their wages, as social security welfare did not cover AIDS treatment expenses. A Participant described how she had suffered from living difficulty with less money:

(Social security card) should include anti-viral drug expenses. It's not included. I once asked for it but the hospital said 'No'... I paid for social security welfare every month. I also paid the tax. But why they restricted our rights? They should include anti-viral drugs so we won't have to take a leave due to the sickness. I don't want to be sick. If I had TB, the social security can cover TB drug. But if I had TB, I would be dismissed also. Actually, the anti-viral drug expenses should be included in the social security. It's only 1,500 per month. Nowadays, although anti-viral drug is cheaper, the doctor gives me 14 pills as trial. It might be difficult to pay by myself since I earn a low income. How can I manage it with my low income? I have to send money to my mom and my children for their living expenses...

Fe7Ra, 234-241/7

The social security scheme covers clients in designated hospitals except referring care at the hospital nearby. Thus, patients cannot use continuous health service or home care services. The patients with HIV/AIDS who receive anti-fungal medicine at a Day Care in the afternoon and went back home in the evening got worsened symptoms and had to be re-admitted resulting from the limitation of social security schemes.

Toon, 35 years old, had to be treated for cryptococcal meningitis in the hospital frequently due to the discontinuous anti-fungal drug when being discharged from the hospital to Day Care services. From her suffering experience in 20-day Day Care treatment, she said:

First, when I came back to my husband's house, I was able to catch a bus to the hospital in the morning. However, in the evening I couldn't do that at all. The anti-fungal medicine made me dizzy and very tired. I wanted to vomit. Sometimes I had to catch a taxi back home. Afterwards I felt tired every morning. I myself could not go to see doctors. I used to go [to see doctors] by bus, but on the way

back I fainted in the bus..... I was so exhausted. Nobody at home looked after me or prepared me a meal. Now my symptom is getting worse and I haven't received drugs for a few days...The hospital didn't admit me as a board-client though I've got a social security card.

Fe1B, 317-326 / 46

Boon used to visit a private hospital for CD4+ cell count and also felt that access to a private hospital service was costly. The healthcare service charge in a private hospital was too expensive to afford. In addition, a social security card did not cover AIDS treatment and investigations. He claimed that he could not access the health monitoring and illness prevention by using security health welfare. He described the unaffordable and unequal social security welfare in a public hospital:

Too bad that there is no lab in a public hospital here. If you want to find out your CD4, you have to go to the private hospital. It costs you 800 Baht for testing CD4 and a thousand-something for other HIV tests. True, it's very expensive. If you want to know CD4, you have no choice. For me ...of course, I want to know my CD4 to prevent myself from any opportunistic diseases. If I have CD4 lower than 200, it is possible for me to have opportunistic diseases. So I have to pay money for myself for this test... It is very hard for poor workers. They can not afford for this test. The social welfare does not cover it...Our rights are not equal to government officers' right...

M2Phu, 411-416 /13

Inequity service between paid treatment and welfare treatment

The participants who had social security card often chose private hospitals near their work place to utilize health services. Participants had experiences of not receiving quality of care and facing discrimination from health providers. Tuk was a patient with tuberculosis, and she received a treatment at a private hospital. She experienced discrimination in the private hospital. She also felt that she did not receive equal care and treatment compared to the ones who did not have a social security card and paid for the medical cost with cash.

They [doctor and nurse] didn't give me special care. I felt bad that I used my social security card to pay for medical cost. I thought that they took a good care of the patients who paid by cash. The room was not very clean. I had to wait for an hour for a nurse when I called her. The nurse was very moody when taking care of me. The doctor rarely checked on me. There was someone who came and asked about my illness history. I had no idea who that person was and why that person asked me that way. I told the person that I had been infected for 7-8 years, and she didn't believe me. I strongly felt that she discriminated against me.

Fe2Su, 17-22 /1

Summary

The study of the National Plan and Policy for AIDS care concludes that the AIDS care policy lacks clear-cut management and distribution of resources and healthcare manpower in the multi-levels of healthcare systems. The tangibles plans of quality, standardized HIV/AIDS care and equal access to healthcare services are not set up. In addition, the models of holistic, continuum, and comprehensive care such as community-based care and home healthcare are not well implemented practically. However, in order to make the suggestions and inform the HIV/AIDS care policy makers, investigators have to study the existing strategic plan of care and services policy implemented for persons with HIV/AIDS in Thailand and other countries.

This chapter discusses the findings regarding persons with HIV/AIDS' experiences in healthcare systems. The participants described the structural constraints in healthcare systems in terms of service provision constraint, constraint of treatment and care, sub-standard healthcare environments, and constraint in healthcare coverage. The participants also explained service provision constraints that blocked them from accessing quality, equity care and services. They described constraints of treatment and care that obstructed most of them from accessing quality treatment such as anti-retroviral therapy and adequately continuous care. In addition, they faced with sub-

standard healthcare environments that hindered them from receiving quality, continuity of healthcare services. The substandard healthcare environments that were composed of unqualified medicine and unscientific alternative therapy were also mentioned, including lack of healthcare information to prevent illness and to promote drug adherence, or lack of continuous and effective referral systems. These made the participants unable to gain access to health promotion and prevention services to maintain their health status. The constraints of healthcare coverage that did not cover treatment of AIDS and investigation that impeded participants from receiving health promotion, symptom monitoring, and prevention of illness were also experienced and described by the participants. In short, patients with HIV/AIDS could not have benefits or gain proper facility from health welfare.

CHAPTER V

FINDINGS PART II: HINDRANCE IN ACCESS TO HEALTHCARE AND SUPPORT

This chapter presents the finding part II of narrative analysis of participants' interview data. These findings describe the factors that hinder persons with HIV/AIDS from accessing healthcare and support. These results are illustrated in terms of health personnel hindrances, personal weakness, as well as community and society hindrances.

Hindrances in access to healthcare and support

Participants who have experienced in utilizing healthcare services discussed the difficulties that obstructed their healthcare access. They described the factors that hindered them from having access to healthcare and support. The findings are categorized into three categories: 1) health personnel hindrance, 2) personal weakness, and 3) community and society hindrance. The factors that hindered their access to healthcare and support are described and exemplified with details and verbatim extracts from their stories (names used are pseudonyms).

Health personnel hindrance

There was a multidisciplinary team of healthcare providers who provided care for persons with HIV/AIDS. Most of the participants expressed that the healthcare providers hindered them from receiving the information of care and treatment as well

as social support. The characteristics of healthcare providers as they described were divided into prejudice approaches, no human care, and no human right protection.

Prejudice approaches

The participants who were the representatives of HIV/AIDS clubs expressed the negative experiences in healthcare resulting from the government's prejudice. They perceived that the treatment provided for persons with HIV/AIDS were limited and unequal because the government separated the types of health welfare for population groups such as government officers, labors, and other people. A participant expressed the unequal right of health welfare with the government's bias as:

It is not fair....I think we do not have the equal right in the health policy because the government separated the equal right of healthcare for Thai people. Government officers can have the most welfare of AIDS treatments, the labors can have only the right to symptomatic treatment like general people. We also pay the tax as equally as other people. Sometimes, the workers had to pay the tax more than government officers. But government welfare has more right and facility than social security welfare. Why do government officers receive better treatment than us? Why don't the government consider that everyone who pays the tax have equal right to the treatment?...

M4Phu, 437-451/10

The vision of the government and policy makers is the main factor in establishing the health policy to serve persons with HIV/AIDS' needs. However, persons with HIV/AIDS received the discrimination from policy makers via the public. A gay participant expressed the prejudice of the government:

I watched the program about 30-Baht gold card on T.V. Why did the government exclude AIDS treatment from the 30-Baht gold card? I was hurt because the government said that we are people with misbehavior ... we are promiscuous...we have the disease which deserves social rejection. We have to take responsibilities for ourselves..... the government discriminates against us...They hate AIDS people, so they don't want to support us...they want to reduce the number of AIDS people.....

M4B, 913-917/25

Most of the participants perceived that good or bad services they received depended on the quality of healthcare providers they met. The prejudiced and unqualified counseling skills as well as no updated information of treatment and care from healthcare providers made them deny having voluntary blood tests. As a result, they could not have early treatment to prevent AIDS progression.

Anan, a male participant whose symptom developed to the last stage of AIDS and lymphoma, told about his experience on pre-counseling at a private health setting in 1998. Anan decided not to have a blood test because he felt that it was useless to know the blood test result without any treatment, and he received insufficient information from a general physician. He described a general doctor who provided unmet health information as having unskilled and prejudiced approaches. He stated:

The doctor said ‘If you wish to have a blood test, you can do it. For the advice on a treatment when finding the disease, there is no progress.’ It’s just a testing and not useful. The doctor should have advised me about the medicine. I continued my question, ‘What should I do if the test reveals I have infection?’ The doctor said, ‘There is only one alternative that is reading Buddha doctrine books.’ The doctor did not inform me of any available medicine or give me any advice. What a bad luck I had to meet this doctor! He had no vision. He thought I was a bad guy, and there was no need to cure me....

MB6, 253-256/7 261-267/8

Some sufferers claimed that they received unqualified counseling services from healthcare providers who had prejudged AIDS as a unsightly dead judgement. As a result, they were depressed with the dead sentence from the doctors when they were informed that they had HIV infection. These made them attempt to commit suicide. A female participant described a healthcare provider’s negative attitude towards AIDS:

How prejudiced the first doctor I met was! He determined my life! The doctor told me that I could be alive for only three years. ‘Whatever property you have, transfer it to your family or relatives’, said the doctor. He thought AIDS was a dead sentence and I would die very fast. This statement pounded in my head all the times. I might have had a hope to live if the doctor did not say that. I had no hope at all. I could not stop thinking of my terrible image when

I am sick....I am the person who is well-known in this city. How could I face my future image? I will have ugly face and skin and show my AIDS symptoms. No! I do not want to. I wish I were dead. That was why I wanted to kill myself...

Fe3B, 38-43/2

Participants who were volunteers said that personal prejudice hindered them from doing activities to support their groups. They had difficulty and were unsuccessful with the services when they cooperated with the government officers who worked in the sectors related to HIV/AIDS. A HIV/AIDS volunteer described the ineffective cooperation from biased government personnel:

I was discouraged...I tried to do many things for our group...such as improving access to care, occupational training, and basic support for the sufferers. I was the representative of our group to join public health personnel, social workers, or public attorney...At the meeting, they all accepted the cooperation of AIDS care and support. But in reality, I was rejected from the social workers when I took the young AIDS mother and her one-month-old baby to request for the household support. She had no money but they refused to help her. They persuaded her to go back to Chiang-rai without giving any intensive support. I analyzed that only few officers tried to implement and cooperate AIDS care and support. But almost all of them did not work or cooperate because the healthcare providers and the government offices still objected to AIDS people.

M3Phu, 924-929, 931/ 12, 954-955/13

No human caring

The majority of the participants who were informed that they were HIV infected did not receive any voluntary blood test nor pre-and post-counseling by healthcare providers. They realized that they would be getting worse by AIDS when they were informed of the blood test results. Almost all of them were suggested to do blood test for immunity level in order to apply for the anti-retroviral therapy project. However, many of them were excluded from the project because they had low immunity. They felt that they were neglected and left without care, and received

inadequate psychological support including information about the disease and its treatment.

A female participant expressed how she was hopeless about her symptoms when she was informed of the result of blood tests. She regretted it because she did not have any treatment and care including being denied access to anti-retroviral therapy due to her low immunity:

The nurse took my blood for CD4 count. I had no idea what CD4 was. The nurse rarely spoke to me. She once said that she was looking at how much immunization I had. My CD4 was very low. The nurse was stunned and exclaimed 'Oh! I could not believe that you have such a low CD4. I could not register you with the project.' I was spaced out with the nurse's words. I sat in front of the clinic for an hour. I didn't know what to do or where to go. I didn't know how to go home. I was lost! How cruel she is! She should have asked me how well I was, how well my family was, how well my parents and I get along, if I faced any complicated symptoms, or any questions that were not too harsh for me....She should have advised me where I could receive treatment...afterwards....

Fe2 Su 119-130/ 4

Many female participants told the story that healthcare providers did not respect them as a person. They faced with healthcare providers who assumed they were bad persons. They were distressed because health professionals had prejudice against them and did not provide any good information for them. A female participant expressed her sentiment:

Do you know why some AIDS patients die easily...Because they were distressed and hurt from bad mouthed doctors...Really, doctors said that there was no need to take any drugs. There was no drug for us now.... until next life also. Although we wasted our money and tried to find money by selling the farm, the house, and the land to buy the anti-viral drugs, we did not have its benefits. They said AIDS could not be cured. Doctors pushed me to go back home...to accept the truth. I think some doctors did not have any good morals or ethical practices. Doctors said things without giving any encouragement and mental support. They assumed all women who were HIV infected were bad

people. When we visited some doctors at hospitals, they did not pay any attention to us...

Fe6Phu, 570-577/17

No human rights protection

Persons with HIV/AIDS always faced the situations of no human right protection. They were forced to expose their health status when they utilized health services especially at the emergency room. They expressed that healthcare providers who had the authority did not protect their human right. Persons with HIV/AIDS who suffered with their physiological symptoms felt distressed with emotional and mental constraints. Here was a story of a female participant. She claimed about receiving voluntary blood testing when she came to the emergency room. She was sorrowful that her right were violated and her confidentiality revealed:

When I refused to have my blood tested, they suddenly doubted what sickness I had. They asked me about my former illness....I couldn't reply. I was blurred and tired. I didn't answer and stayed still, but they were eager to check my blood...They said that if I denied the test, they would pull out my oxygen and take me out of the room. They talked to my cousins...forced me to sign that I refused the remedy. ...I couldn't breathe. ...very tired...Thus, I allowed them to do the test...I was quite sad at that time. I was sad... Why? Why did they force me like this? They did not protect my right. OK, I surrendered unwillingly. Umm...when the result was shown, they came to see me – with gloves...the female doctor asked 'You know what illness you have. Why didn't you tell us at first...didn't tell.... You know what disease you've got?' I said sure. 'Is it AIDS?' She asked me very loudly. There was not only me. The other clients were on the next bed. They could hear it easily...

Fe3B 878-881/ 24, 890-894/25

Kanya, 30 years old, was two months pregnant. She wanted to keep her pregnancy because it was her first baby. She said she was forced by a gynecologist to have an abortion. The doctor did not inform her about the free available service of anti-retroviral drugs to prevent HIV transmission to fetus for pregnant women. She told the story that the doctor did not protect her right with regretful emotion:

The first doctor mentioned it was costly to cover medical care cost if I kept my baby. That convinced me to think of how to manage a medical expense...He did not let us have the time to consider about my baby.....The first doctor didn't tell me about the information of anti-viral drugs to prevent AIDS transmission to the baby. He said everything ...medical care cost was expensive, so I should not keep the baby.....The baby would have a 50 % chance to get AIDS....He forced me to have an abortion...I didn't want to get rid of my baby. I was afraid of sin. I regretted that.

Fe7B, 119-127/ 4

Personal weakness

Personal weakness was a personal factor that primarily hindered persons with HIV/AIDS from having access to care and support. Participants' personal weakness was categorized into self-refusal of care and support, economic prohibition, and poor health status. They described their personal weaknesses as follows:

Self-refusal of care and support

HIV/AIDS was still a sensitive issue, and some communities did not accept persons with HIV/AIDS. Thus, persons with HIV/AIDS did not reveal themselves in the community. They perceived that family would have difficulty if they disclosed themselves to community so that they refused to seek healthcare and support. A female participant who declined to receive home care from healthcare providers indicated her reasons:

There was a home care program. The doctors asked me whether they could visit us at home. I did not let them. My husband's family did not want to disclose his condition to the community...His younger sister was a good woman, studying in college. My husband was afraid that she would be embarrassed. We did not want our family to have any difficulty from us...

Fe5Su, 532-538/15

Some participants refused treatment of AIDS or lost the opportunity to access the special care and support because they did not want to reveal themselves to family and community. They were afraid that some treatment might force them to disclose

themselves as patients who had AIDS symptoms resulting in rejection by their family.

A female participant gave her reason for refusing AIDS treatment:

The doctors suggested that I apply for the anti-viral project, but I was not interested in it. I had never told my family that I had AIDS infection. It was still my secret. I didn't want to take anti-viral drug because its side effect would make my skin blackened and cause hair loss like some of my AIDS friends....I was afraid that my family would know the truth that I was AIDS patient. They would reject me. If I got sick and thin like this, I would tell them that I got sick because I had DM and cancer.

Fe 3B, 537-540/17

In some provinces, there were a lot of social welfare funds provided for persons with HIV/AIDS who needed social support. However, they had to reveal themselves as AIDS patients so that they could access the funds. The participants were afraid that public disclosure would have negative impacts on them. A participant who was an AIDS volunteer explained the reasons of persons with HIV/AIDS who refused to receive social support:

There are a lot of social welfare funds for AIDS patients in this province. But a lot of AIDS patients could not access these funds because they did not want to come here (provincial social welfare). They had to reveal their AIDS status to receive the support. But they were afraid of disclosing themselves to the public. They were afraid that the community would reject them. Here, no one suspected them but they perceived that others would recognize them. We tried to announce that there were 100 of funds to support them, but only 20 of them came here to receive it. They did not want to come here....

Fe7Phu, 808-812/23

Economic Prohibition:

No money, or limited treatment for the poor

More than half of the participants had no income and were unemployed due to their chronic illness. Furthermore, economic problems caused them to get worse. Participants did not have enough money to spend on their living. Therefore, their parents and relatives supported them. On the other hand, some participants who did not have any financial support from any sources such as public health cards struggled when accessing healthcare

services. Not only did they have to respond to a medical care cost, but also other expenses, such as traveling when visiting a healthcare setting. Hence, having a financial difficulty was one of hindrance factors leading to a lack of continuum of care and treatment and causing ineffective prevention of the illness. These following patients' stories would reflect the economic struggle the patients had.

Samart, 36 years old and living with AIDS quit his job due to his severe illness. He depended on his relatives who were poor and could not afford the anti-retroviral medicines for him. Samart, therefore, did not continue his medication.

Most patients are jobless. They can't work, so they have no income. Frankly, anti-viral drug is also quite expensive. How much? Each dose costs more than 1,000 – 2,000 Baht. The whole expenses are over 20,000 Baht. So, where can I earn money? Why asking siblings or parents for help? They are poor, too. Sometimes I could ask them for a small amount, yet sometimes I got their criticism instead. I had to take anti-viral drug continuously. Drug would become useless if I stop it... Now I have decided to stop taking anti-viral because I have no money... I can't deal with this situation.

M2B, 450-454/13

Poj is an AIDS infected patient with tuberculosis. He quit his job to take care of his wife who was very sick. After his wife passed away due to fungal meningitis, he could not continue the tuberculosis (TB) treatment because he could not afford the medical cost and transportation to the hospital. He became worse and could not work. He had to rely on his relative. He described his economic problem that caused difficulty in access to care:

The doctor told me to continue TB treatment. I did at the beginning. Later on, I couldn't. I had to pay for traveling and other expenses. I had no money to pay for TB drugs. So, I stopped taking the drugs for 10 or 20 days and started again. At that time, I was facing the severe trouble because my wife just died. No one I could turn to. Firstly, my older sister didn't accept me, but she did later. Although she takes care of my kid and me, she does not have much money to pay for anti-viral drugs. I spent all money that my wife and I had saved when my wife was severely sick. I couldn't work because my body is still weak. I have no money to buy anti-viral drugs...

MM1B, 335-545 / 10

Due to the high cost of anti-retroviral therapy and no opportunity in access to the hospital's program, Jo and Samorn living with AIDS in the end stage could not receive anti-retroviral treatment. Although they came to receive treatment in a university hospital where there are AIDS experts and special clinic, they could not receive the quality treatment as experts had suggested. Participants expressed their economic constraints that blocked them from accessing a quality therapy to prolong life:

The doctor suggested that my husband and I take anti-viral drugs. It would cost over ten thousand. I negotiated with the doctor, 'Can both of us pay for 5 or 6 thousand?' The doctor said nothing. I thought that it might be more expensive, so I decided to end my question. At the beginning of 2001, my husband was very sick. The doctor said that anti-viral drugs would help, and he would be better. But my husband and I didn't take any anti-viral drugs until now. And the doctor didn't say anything. I thought that we have no money, so we don't have the right to get anti-viral drugs.

Fe5B, 991-1004/ 28-29

Pui, a 36-year-old low-income patient with AIDS living in Surin, often borrowed the money with high interest rate when she had a serious sickness and needed treatment and care at hospitals. As a result, she was still in debt:

I have to see him (a doctor) when I am very sick. I have to borrow my neighbor some money to see a doctor. Luckily, the owner of a grocery store right in front of this Soi (lane) sympathized me and lended me the money. I paid 10% (a month) for the interest. I borrowed a thousand, and I paid a hundred for a month. If I borrowed for two months, I paid back a thousand and two hundred Baht. I still haven't paid my debt a baht yet. I have to go to Surin Hospital and Garb Cheng Hospital. I don't know when I will get better. I have to fight to survive! I will go anywhere to get the (HIV/AIDS) treatment.

Fe3Suk, 816-837 / 21

A female with low-income did not receive the anti-retroviral therapy or the investigation of the immunity level. She discussed the less opportunity of anti-retroviral therapy that the poor AIDS family had. In addition, she expressed her

sadness because she could not help her daughter who had AIDS symptoms to access AIDS medicines:

For the treatment of AIDS drugs, although I don't have the opportunity to apply in the projects, I want my kid to be selected. Other parents who have enough money can buy the drugs for their kids about 3,000 Baht per month. I myself don't have any money or how to earn money to buy the drugs for my kids. Now, she cannot go to school because she has a lot of pimples. Some are infected... some are bleeding ...and she is very thin and very weak. My kid shows her bad symptoms. I sympathize my kid very much but I cannot help her anymore...

Fe6Pha, 163-180/3

Some participants who were middle-class and did not have any health welfare could afford the cost of treatment and care when they first accessed health services. However, the high cost of care and treatment made them have economic problems later on. As a result, they could not afford the new regimen of continuous anti-retroviral therapy resulting in suffering with chronic illnesses.

A widowed participant who had illness related to the progression of AIDS gave the reason for discontinuing the anti-retroviral drugs used:

I stopped taking anti-viral drugs at this moment because I had drugs resistance. I cannot use all local anti-viral drugs because I have drug reaction. The doctors suggested that I use new anti-viral drugs from America but I did not have enough money to buy them. I had been treated with anti-viral and paid by myself for many years. Now I lost a lot of money for this treatment. I have to keep the money for my living, so I stopped taking anti-viral drugs.

Fe3B, 1791-1795/49

The poor suffered with high cost at private health sectors

The government has promoted private healthcare setting to participate in providing healthcare services to clients. The participants shared their experiences of access to healthcare services that were close to their houses. Most of the healthcare settings were private health sectors. There was no measure of standard and fair cost of care and treatment leading to lack of consumer protection on medical cost. They had

to utilize that healthcare settings when they had acute illness like emergency care.

Participants expressed concern about the too high cost of care of private health settings. Although the private healthcare settings were close to their house, they could not utilize health services because they could not afford the high cost of care.

Danai, who had symptomatic AIDS with fungal meningitis, once had a serious headache, and he had to utilize services at a private hospital near his house in Samutprakarn Province. He was diagnosed with cryptococcal meningitis and was treated as an emergency case. He expressed the unfair and high medical care cost:

When I first came here, I didn't take anti-viral drugs. I took Fluconazole (anti-fungal drug) because I had a bad headache. The private hospital charged me on Fluconazole for 1,200 Baht (10 pills a pack). I found that it costed only 200 Baht per pack in a drug store. However, the doctor gave me 3 packs of Fluconazole. I paid almost ten thousand! I was shocked with the high price. It was incredible! How could that be! It was 7-6 times of the price outside. They made money from selling drugs or plus a visiting cost --to see a doctor--was very high, too. I was terrified!

M5B, 177-186/ 5

The persons with HIV/AIDS were required to show the level of CD4 + cell counts before being selected to the anti-retroviral therapy project. Participants had to spend their own money on the test because the public healthcare scheme and social security card did not cover this special test. In some provinces, the public hospital lacked the special laboratory to check CD4+ cell counts. Thus, participants had to go to the private hospitals instead, and that made participants spend high cost of lab test. Some of them had to spend a lot of money for special test. Some had to pay for transportation to other provinces as well. A participant, Chard, explained the difficulty of access to expensive tests:

Comparing the cost of having a test on CD4, there was not standard price in different hospitals. It costs 380 Baht at Chula Hospital, 680 Baht at Maharad in Nakorn Si-Thumrad province, but here (private hospital) I have to pay a thousand. Don't you think that I have to pay more plus the cost of traveling,

food, and a place to stay if we go to other provinces? That costs a lot! How about the one who had the test but was not qualified for the anti-viral program? That was a waste of time and money. It was hard for patients with AIDS to have even 500 Baht. I think that poor people with AIDS have less chance to get into the anti-viral program.

Fe1Phu, 624, 626-629 / 19

Poor health status hindering earning income and paying for care

Almost all participants were heads of the family and earned money for their family and children. When they had poor health status due to chronic illness like AIDS, they could not work effectively resulting in loss of productivity and household income. Thus, they could not have the money to spend on traveling to the hospital and receive continuous care.

A farmer who had been HIV infected for 10 years and still did not take anti-retroviral drugs lamented about the suffering of losing the ability to work. The production was decreased and brought him economic problems afterwards. He had poor health status and could not earn money for his living or payment for transportation to a healthcare setting in another province:

Since I was HIV infected, my productivity has decreased. I can work in the fields only one of 10 portions of one day. The crops also decreased. Now I'm in suffering. I have to rear my children and take care of my wife. If I had medicine or full treatment, I could possibly work in the fields to sell more rice and have no need to borrow money. Now I am very sick. I am very tired to go to provincial hospital. The hospital is very far from our village. I always get sick after going back from the hospital. The doctors never give me the anti-viral drugs. I got worse and have given up on going there....

M1su, 472-477/16

Participants who received the treatment discussed the side-effects of anti-retroviral therapy and opportunistic drugs that made them sick. They confronted uncomfortable symptoms that affected their role, especially their work, duty of child care, and daily life. Thus, they discontinued receiving treatment to maintain their roles.

A female widow got sick from drug reaction and discontinued the treatment to take care of her child:

How could I go on taking anti-viral drug? It's like a morning sickness of pregnancy and sometimes I vomited and was dizzy. I felt like I would die from taking anti-viral drugs. Last month my kid was sick so I had to watch over him every day...less rest...I was fed up with food. You know? I fainted at the hospital's gate then I was sent to the emergency room. I can't bear it at all. My kid's ill. Who will look after him if I become sick because of drug's effects? That's why I stopped taking anti-viral drugs.....

Fe2R, 1010-1014/33

A female participant who had AIDS with TB infection gave the reasons for losing follow-ups because she was sick from the side effects of TB drugs:

The doctor gave the anti TB drugs and I almost finished them. I did not know why I was very weak. I could neither get up nor sit up to pass urine at the toilet. I slept in my bed all the time. My eyes were blurred and I could not do anything. I could not go to the hospital alone because I was very sick ...Two weeks later, my father came to visit me, and he took me to the hospital. The doctor said I had an overdose of TB drugs. The drugs made me sick.... I could not do anything....

Fe6Ra, 342-347/10

Community and society hindrance

Lack of family support and network became obstacles for persons with HIV/AIDS to gain access to care. Participants recounted their sufferings when they could not take care of themselves and when they could not keep on treatment. Due to lack of family support and the difficulty of community access, participants confronted family problems and illness problems. They narrated the difficulties of accessing care resulting from lack of support and resources which were categorized as follows:

The poor HIV/AIDS and their family could not afford to be caregivers

The negative experiences in access to healthcare resulted from lack of social support from the family. Persons with HIV/AIDS who depended upon family caregivers could not access healthcare because their caregivers were low-income

persons. AIDS family caregivers did not have any money to take them to and look after them at the hospital. Lack of family supports made them have health impairment and unable to receive care and treatment at healthcare settings.

AIDS volunteers described the poverty and earning difficulty of AIDS caregivers living in a village far from the hospital. Poor AIDS caregivers could not afford themselves to take care of AIDS patients in the family:

..... There was not one healthy person in the patients' family. It meant the whole family was also sick. Exactly, they were not physical ill by the disease but by giving care to the real patient. They, thus, left their work, didn't they? The expenses increased, whereas their income decreased. Supposed that their parents were fishermen, right? Yes, the family would have the fish as their meal. If they made a living and earned 80 Baht per day, they could buy their meal day by day. And then? They left their children at home. The sick children had to help themselves and stay alone...unable to go to hospital due to lack of money...like these patients. They couldn't walk, just lying down all day. Their parents went out to work in the field. ...

Fe8Pa, 1116-1119/ 19

A participant, an AIDS volunteer, explained the barriers of taking care of patients with HIV/AIDS who depended on their poor caregivers:

Most of AIDS patients with severe sickness were left in their home because their family did not have enough money to take them to the hospital. They did not have money to buy food while they took care of AIDS patients at hospitals. Although patients could use public health cards and eat free food at the hospital, caregivers had to buy food, pay for transportation...and many other expenses by themselves. It was a very big problem for them. It was very expensive ...Umm they did not have such money, so they left their AIDS patients at home....

Fe8Pa, 1125-1132/20

A 22-year-old female widow, with symptomatic AIDS, did not receive enough support from her family. She was worried about her poor health status and her bearing no income because she could not take care of her young child:

...I'm just worried about my child. If I die, who can look after her? My daughter is so young, only two years old. I can't rely on anybody even my

parents. I'm afraid they would refuse to take care of my daughter. My mom has a new husband, so I have a lot of young brothers and sisters. They cannot rear my daughter well. They're poor, too. Who will take care of her after my death? Now I'm so worried because I cannot earn enough money. I hope I could live longer to see her grow up enough, (but) I've some AIDS symptom...When I am thinking of my short life, I'm so worried about my child.

Fe5Ra, 615-617/15

Participants who were caregivers and widows could not take care of their AIDS children because they were faced with problems related to AIDS alone. Somsri, a mother of a 7-year-old AIDS infected child, discussed the unsolved problems about the sickness of her child and herself:

I can't find the way to solve problem solving...Nowadays, as time goes by, I'm more confused and busier. I could not take care of him as well as I can. I don't have any financial support or advice from my parents because I am afraid that they will reject us. My child now gets worse. I'm not sure whether he could live long or not. Without him, who will live with me? I don't know how to cope with my live in the last stage of the disease.

Fe6B, 1027-1030/ 32

Being left out from family's support

Participants who were widows told the stories of family conflicts with their husbands. Their HIV/AIDS related illness reduced sexual desire and practice. Their husbands then left them for a new wife that made it even harder for the participants to run their life on their own. They had to be responsible for their kids and had no one to consult. They expressed the depression they had:

Pim, 23 years old, was sick with pneumonia (PCP) at the end stage of AIDS. Her husband left because she was too sick to have sexual intercourse with him. She bore all burdens with her ill child while she was sick:

Look at me! I am very sick. I don't want him to be ashamed with his folks. The doctor suggested that I try not to have sex, or else wear a condom every time. To tell you the truth, I had no sex drive at all! So I told my husband that I was too sick to sleep with him. He told me that he would find a new wife. He didn't care for me. He started seeking for a new girl. I don't know what to

live for (crying). I am worried about my kid. I remember once I was very sick, I felt like crawling instead of walking. He never took care of me. He didn't pay attention to me. He didn't come back anymore. Now I don't have any support from him. I have nothing. I don't have money to go to the hospital and take care of my kid.

Fe2 Ra, 262-274/ 10

Ubon was a mother with a three-month-old baby who shared her feeling when she was neglected. She had to face with many problems, she had no one to depend on, and she was very depressed. She was thinking of committing suicide to get away from the problems:

I was very depressed. I had to face the truth that my husband rejected me. He disregarded me and didn't give me any money... But how come my husband didn't love me anymore? Perhaps because I can't make him pleased. I cannot have sex with him. He also neglected our baby, and seemed to think like the baby didn't belong to him. I had to look after our baby alone all the time and never rested. I could not eat well ... It was so gloom when thinking of my disease...I don't know who I could depend on...don't know who I could express my feeling with. I was so busy with the baby and that didn't go to the hospital...My baby was only 3 months old...I am also worried about him...but no one help me..... After feeding my baby at night, I said good-bye and sorry to my baby. I used I tied a rope with the house's beam and decided to commit suicide...

Fe4Ra, 245-251/ 8

Discrimination in work and earning income

The aversion and negative reaction of the community affected persons with AIDS who revealed themselves. There was still discrimination of AIDS in community that made persons with HIV/AIDS have difficulties in earning their living and have no income to spend on cost of transportation to healthcare settings. Although some of them are still healthy, they have no opportunity to apply for work in the community. As a result, some of them went to find job in another province.

Bua-kam, a 32-year-old healthy client described the hardship of job application in her province:

Nowadays I have no job, and no money for healthcare and traveling expenses. If the government wants to give us a hand, it should help infected persons to get a job. Because when they apply for work, hospitals have to describe in the health certificate that they are HIV infected. Then they lose the job. I want the companies to employ infected persons. I think they should employ us since we're still healthy. I used to show my health certificate that I was HIV infected when I applied for a position in a factory... they said 'Oh my goodness... we can't employ infected persons.' Maybe they were afraid that I would spread this disease to others.

Fe4Su, 1135-1143/28

Joy, a widow with a one-year-old child, worked as a laborer in the factory. She faced with the discrimination in her workplace. Her co-workers wanted her to be laid off the job. Joy ignored them because she needed to work to raise her child and family. She isolated herself and she had no social support, as she stated:

The foremen forced me to leave the job. I gave them the reason that I had to take care of my mom and my only child. I said, 'If I can rely on my relatives, I will leave.' They told me that they didn't discriminate against me. They were worried about me and wanted me to leave job to seek for treatment. I persisted for the same reason. Then they started to scold me. I listened quietly. They asked again whether I wanted to leave or not. I told them that I was still healthy and could work. They asked, 'How long do you think that will last?'

Fe7Ra 180-189/ 6

In the northern part of Thailand, the commercial sex workers who were sick with symptomatic AIDS went back to receive treatment at healthcare settings in their hometown. When they recovered, they could not work in the farm because the landlords did not want to employ them. Thus, they went back to work as sex workers in other provinces. Nok, a volunteer with HIV/AIDS, narrated the situation of difficulty in earning income in her hometown:

Most of the women with AIDS went to find a job in other provinces when they got better from the sickness. Most of them used to work as sex workers. ...Really, most of them who revealed themselves as HIV infected patients could not find a job in our community. Our community did not employ them to work in the farms. It was a very hard job because they had to work in the fields to plant rice. ... These women (sex workers) did not want to work hard in the farms and no one employed them any way.... So, they decided to work as sex workers again. Many of them came back here to receive treatment when they

got sick, and some of them went back to work again... We know all of them who live in this area of Dork-Kumtai and Pu-Kamyao.... There is no job for them.

Fe2Pa, 740-749/17

Five women from 30 women with HIV/AIDS continued to be commercial sex workers after being HIV infected. Economic problems found in female participants who had asymptomatic HIV infection forced them to become commercial sex workers. Although they certainly knew that it had disadvantages, they had to be sex worker as it was the last way to earn money for themselves and family. For instance, they worked as sex workers away from their provinces like in Bangkok and tourist provinces in the south.

A participant who had pneumonia (PCP) and severe illness talked about her necessity to be a commercial sex worker in the south for 3 years because there was no job in her hometown. She had to earn money for her poor family who lived in Phayao. Thus, she had to leave her hometown and travel to work in the southern part of Thailand.

After coming back home, it took a few days to accept the truth that I had already been AIDS infected. Doctors did not tell me any detail of treatment and how to protect myself. No exceptional symptom to worry. My health was absolutely strong, so I didn't think of treatment because I had no money. Firstly I did not decide to have any blood check again...because I did not have any symptom. Thus, I was not sure that the blood test was accurate...I could not live day by day because my family was poor. That was why I had to return to work...suddenly I came to Ko-lok (district)...There was a woman who used to live in my village who urged me to come here because I could earned nice income. I came with her as (we were) cousins...from the same hometown. I've lived here and worked as a prostitute since then.

Fe1PhuK, 127-129, 138-150/5

A widowed participant described the difficulty of finding a job in a company because of HIV/AIDS blood screening blocked her in applying for a permanent job:

I finished only grade nine. I cannot find a good job. I used to work in a company where HIV/AIDS screening is required from all employees. I

resigned from the job when I was pregnant. I cannot find a new job again because every company requests for blood test for HIV. I think I cannot pass the blood screening. I am unemployed because I have HIV/AIDS. I face hardship of my living. I have to be careful of my spending.

Fe4Ra, 663-665/20

Discrimination in access to community resources

Due to the economic crisis, many poor farmers were suffered from being in debt to individual lenders or to the banks. As a result, the government has established the loan fund for farmers' investment. Some healthy participants, who had disclosed themselves as HIV infected, encountered injustice when borrowing for agricultural investment because of the committee's bias. A female participant with three children who lived in the northeast of Thailand described her experiences:

The main problem of us is having no money. They said we have AIDS. When we asked for the loan, they promptly turned it down. As if we would borrow and die before paying back, and they can't collect the debt. That was what they told us. Until now this problem can't be solved. ...Though there's a fund for the village, around one million Baht, they avoid AIDS borrowers. They fear the loss of debt...In fact this fund's aim is to get rid of poverty. The committees are afraid of NPL in case of HIV borrowers. We still want to work and are still healthy. We just want to borrow money for work, not to waste it on something. However, they restrict us, nothing for HIV people ...So, this is a community acceptance problem. Community could help us, yet what they really do isn't as much as it should be.

Fe3Su, 345-552/16, 553-554/17

Thong, a participant who was asymptomatic HIV infected and healthy, disclosed her AIDS status in the village and could find work in a rice field. She took care of her old parents and her children. She explained constraints of the Village Fund that was unfair for persons with HIV/AIDS because the committees granted the fund for others except persons with HIV/AIDS. She was very stressed and that caused her sickness. Sometimes, Thong had to loan the money for family household expenses from the shark loan:

I feel AIDS persons seem like they are alone. If I have no one to take care of, that's fine. But I live with my parents, and I have cows and buffaloes. If I am in debt, I can sell them. The village committee's criteria are not fair. I am strong as a normal healthy person. I can work. I cannot work if I am weak. I bare a lot of burdens. I need the fund for my farm and my daily living at this moment. My future is getting worse. I am very worried. I cannot even pay my kids to school. I cannot think about anything. I can pay back the fund if the committee grant me a loan. I have to be responsible for what I do. I can pay back the money if I can sell my products.

Fe5Su, 836-854 / 24, 860-862 / 25

Lumduan, 38 years old with three children, had chronic illness of fungal meningitis and revealed her status to her community. She suggested her opinion toward the village fund that the village committees did not approve any loan to patients with HIV/AIDS:

I went to participate in the village fund meeting. The committees made it clear in the meeting that they wouldn't give a loan to AIDS patients. They were worried that there would not receive the pay off from the AIDS borrowers. That doesn't make sense. Why didn't they tell people with AIDS to elect them? I am suffering of my living. My right to borrow the fund was limited. They said 'no budget' as an excuse. I also could not receive the education fund for my kid because my oldest son is not qualified. They offered the fund to the child whose parent had a car accident. Where can I get the loan? If the committees won't sign it and allow me to borrow the fund, where can I use the money for my earning?

Fe3Suk, 1657-1665 / 42

Participants described the obstacle in management of health services such as Day Care and counseling services necessary for persons with HIV/AIDS. However, some healthcare settings in other provinces could not maintain these services due to problems about the acceptance from community and the lack of concerned officers' support.

Paka, a member of the HIV club, informed that HIV/AIDS group activity had to be run in the governmental meeting room and under executive permission since community and people felt disgusted by people with HIV/AIDS. As a result, there was no place for HIV/AIDS group to do activity.

For a meeting in that place [School], once there was a gossip about children whose parents were AIDS infected who wanted to play a swing. Yet they were not allowed to do so. When persons with HIV/AIDS had lunch at the canteen, somebody criticized they shouldn't have lunch with healthy people. They [teachers] should have not spoken like this...especially with clients. We can't use hospital's conference room because of this problem...I only wish they could understand patients more. It's not easy to catch this disease by eating together or walking past one another. They shouldn't have objected to us...

Fe3 Su, 396-407 /12

Malee, a volunteer of a provincial hospital's AIDS infected club, described the obstacles in carrying on HIV group activities in a hospital that they did not receive officers' support because of disgust of persons with AIDS. Moreover, government units denied them to use places for conference because the officers objected to persons with HIV/AIDS and their children. That was an obstacle making those AIDS infected patients unable to exchange information among group members.

Once we formed a group and we decided to use the hospital's conference room, but they didn't allow us to because they didn't want us to use their tables and chairs...We used to do group activities at a school hall ...Nowadays, the director of the school does not allow us to use the hall...were they afraid of AIDS persons. Now, we have no place to distribute drugs. We normally do group activities such as seminars or lecturers or presenting from monks. Now, we can do nothing. They're afraid that children in nursery (School) might catch our disease...The director of the college doesn't allow us to sit on the bench. The person with AIDS (whose children are AIDS infected) have to clean the bench and the swings by detergent...We can't stop children to play in the playground, so I have to clean all the toys afterwards. Conference room...is also unavailable. We paid them 500 Baht per month for electricity costs. We only used it 2 times. The group split up. Clients only waited for the doctor till the afternoon. We can't exchange any news in the morning now.

Fe2 Su, 462-470 / 14, 472-481/ 15

Community and society discrimination

Most participants said that they endured the impact on the discrimination from public and society. The social discrimination resulted from the government's ineffective public relations that made the public did not understand or accept persons with HIV/AIDS. Thus, they were rejected from society.

A participant told the story of social discrimination that hindered them from living and accessing the social services:

The community rejection was a very important factor that impeded people with AIDS living in society...because people in community had less education about AIDS...some also had no AIDS education at all. The community got and believed in the information from the former government that advertised AIDS as a dangerous disease. Nowadays, people in society do not accept AIDS ...The spot advertisements make the people fear and frightened of AIDS... So they discriminate against AIDS persons in society ...If the community and society do not have better AIDS education, people with AIDS cannot live normally in community.

M4Phu, 583-591/ 17

The participants who were volunteers talked about the hindrance that made a lot of people with HIV/AIDS could not access Day Care services because they did not receive enough information and they were afraid to disclose themselves to the public. In addition, they perceived that people in society did not understand or accept people with HIV/AIDS.

Nong, 44 years old and an HIV/AIDS volunteer, talked about the limitation of activities in day care services due to the obstacle of the public relations about AIDS services in communities. She was afraid that she would have the negative impacts from society if she disclosed herself to do activities related to HIV/AIDS:

A lot of AIDS patient still did not access Day Care services...I was worried about that... I would like to reveal myself via public to encourage them to join activities at Day Care.... But I am afraid of disclosing myself on air because some people could recognize my voice...I could not present myself via public or radio programs because the society still did not accept HIV people...I also have my business in this city. If my customers know I have AIDS, I will lose financial credit and it will affect my business.... I am very careful about this problem because I have to earn income for my family...

Fe7Phu, 511-517/ 15

A participant who was an AIDS volunteer gave the reasons that persons with HIV/AIDS did not disclose themselves to public because the negative advertisement

made people in society afraid of people with HIV/AIDS and rejected them. Thus, they could not easily access healthcare services and joined the activities offered:

When the spot broadcast advertised about AIDS via public relations, it looked like it was a severe attack to fight against people with AIDS. I could remember it. The first spot broadcast showed the bad images of AIDS patients who had wasting syndrome laid down in bed. Some had skin infection, others felt down waiting to die... I watched the spot broadcast on TV and wondered why the government distributed the frightening spot of AIDS to public like this.... This made the people who did not have the education about AIDS scared of people with AIDS. They were not scared of AIDS but they were afraid of people with AIDS. If they knew that this guy had AIDS infection, they would reject him and get rid of him from society.

M4Phu, 1077-1082/ 30

Summary

The finding part II explored the hindrances in access to healthcare and support of persons with HIV/AIDS. The results described the hindrances that were categorized as health personnel hindrance, personal weakness, as well as community and society hindrance. They confronted with government officers and healthcare providers who had prejudice and did not protect their human right that caused them denied healthcare and treatment in early stages of the disease. Personal weaknesses that were composed of self-refusal of care and support, economic prohibition, and poor health status were also major hindrances of healthcare and support access. Most of the participants who had low income and poor health status could not access healthcare systems because they did not have the necessary basic needs to spend on and utilize healthcare systems. Finally, the hindrances from family and community discrimination were barriers that blocked persons with HIV/AIDS from utilizing continuous healthcare systems and receiving support and acceptance from society.

CHAPTER VI

FINDINGS PART III

EXISTING QUALITY HEALTHCARE: A SMALL CHANNEL FOR HEALTHCARE PARTICIPATION TO MEET NEEDS AND EXPECTATION

This chapter presents the findings part III of narrative analysis of participants' interview data. These findings are organized according to research questions about the factors that facilitated persons with HIV/AIDS in access to healthcare and support. The results described the healthcare system as 'Existing quality healthcare: A small channel for healthcare participation to meet needs and expectation' which implied that only some participants could access and receive the existing quality of healthcare. There was a small channel that few persons with HIV/AIDS had to put efforts to gain access and were satisfied with healthcare systems. In this chapter, the findings are categorized into two categories: 1) Access to information and health system to improve health and 2) participation for needs and expectations in healthcare.

Access to information and health system to improve health

Twenty participants who had positive experience in access to healthcare system were still healthy HIV/AIDS persons. The positive experiences implied that participants could not only access to the health information and quality healthcare system but they also had put their efforts in gaining access to healthcare services and

support. As a result, they were satisfied with the existing healthcare system. In addition, they could solve their health problems and had successfully delayed AIDS progression. These results were illustrated into 5 categories: 1) Opened gate of information and system for self-care development, 2) Own energy effort drive to access healthcare, 3) Accessing to HIV/AIDS clubs, 4) Ability to maintain self development, and 5) Ability to be contributors to healthcare development. The results of the study are explained and exemplified with details and verbatim extracts from the participants' stories by using pseudonyms.

1. Opened gate of information and system for self-care development

The factors that facilitated persons with HIV/AIDS in access to healthcare were health information systems that opened the gate for participants to access and gain the abilities to improve their health. Thus, they had successful experiences in utilizing the healthcare system. Participants described the benefits of health information as follows:

1.1. Meet the suitable healthcare services

The suitable healthcare services were the factors that facilitated persons with HIV/AIDS to utilize health services continuously. The component of this health system that persons with HIV/AIDS felt comfortable and satisfied with when using this services were healthcare providers who are experts, useful health information, and affordable access.

A participant who had been the leader of the HIV/AIDS club described the proper healthcare services that facilitated persons with HIV/AIDS with easy access which were like the services that he had usually joined and participated in:

We have the meeting and join the activities at Day Care in the fourth week of every month.... There were well-trained healthcare providers such as doctors, nurses, nutritionists, and social workers who provided care for us...It was a good service because they did not disclose persons with HIV/AIDS...The service was provided at the hospital on official holidays because a few people went to the hospital. They used the fourth floor of the building for the meeting. So, no one knew and got involved in this activity. There were only us who joined the activities...

M2Phu, 272-275 / 9

The participants who decided to use alternative medicines said that the suitable healthcare services encouraged them in gaining access to qualified herbs. They could receive free services and approved herbs from hospitals. A male participant who usually used the herbs provided at Day Care expressed that:

This hospital produced the dried herbs in capsules for us. It was a free for service. No need to pay any money...We had a lot of herbs such as Menispermaceae and bitter squash. The nutritionists in this hospital also provided mushroom shop for us. The doctors who prescribed the herbs for us had to check our health every month...

M2Phu, 506-508/ 16

Fah was 28 years old with no AIDS symptom. She used herbal medicine as an alternative treatment. She had got the information and had the approved medicine tested in the laboratory of the Provincial Public Health Office. The facility of investigation of alternative medicine helped her use qualified herbs:

Herbal medicine is good. My body was very itchy at that time. After taking it, I could recover from pimples... It worked. I could eat well. When I first went to buy the traditional drug, the folk doctor invited me to see how he mixed it and what ingredients he used. ...He told me about some ingredients like.... Menispermaceae and bitter squash. I brought the herbs to consult the doctor and took it to be investigated at provincial public health office...There was no steroid in it ... the folk doctor had to get some herbs in the forest....

Fe4Phu, 1493-1510/ 43

1.2. Access in gaining and exchanging information

The participants reported on the benefits of healthcare access from health information they received from the healthcare system. For example, participants could

receive updated information of AIDS treatment when they joined the activities of Day Care. They could learn and exchange the healthcare experience from the special course and training provided and supported by healthcare providers and NGOs.

Noom, a 30-year-old male participant, described the benefits of the meetings supported by Ministry of Public Health and NGOs. He could receive information about AIDS treatment and exchange healthcare information among groups:

I had to reveal myself at the provincial meeting among our groups. All the participants were people with HIV who came from almost every province. The meetings made me have global visions. I got to know many people and got many friends. We could share our experience and learn from others' experiences. I came to know others who could recover or still lead a healthy life. The resource persons also provided with us the updated treatment and health information. I could get this knowledge to inform and share with our group, too.

M4Phu, 516-518, 520-524/ 15

A 44-year-old widowed, a former leader of HIV/AIDS club talked about the facilitating factors that encouraged HIV/AIDS groups to conduct their activities. The support from government and NGOs networks promoted HIV/AIDS clubs to participate in healthcare services and support. They could receive and gain the updated knowledge of AIDS treatment, medication, and care from healthcare providers, as she said:

Our club had connected with the healthcare networks... We had a meeting every month with provincial AIDS committees. I also had a meeting with provincial social welfare. I received the knowledge of writing a proposal for the funding project with AIDS working groups. We got the better knowledge of AIDS, and updated information of anti-viral drugs. We sent our representatives to attend a conference with AIDS networks...and brought the knowledge back to share with our group...

Fe7Phu, 773-779/ 22

2. Own energy effort drive to access healthcare

Participants told stories that they were successful in utilizing healthcare services and supports. They could access to services that facilitated them to overcome the grief and start to cope with their health problems. They could not only gain knowledge from healthcare providers and other health information, but also put their effort to practice healthy lifestyle for themselves. For example, they were aware of illness prevention and performed health promotion such as having a regular exercise and eating nutritious food. Some of them could recover from a chronic illness because of effective treatment of anti-retroviral medicines and continuous care. Some of them worked as volunteers and contributors. Participants described their own energy efforts drive to access healthcare as ability to access quality healthcare and support to meet needs, accessing to HIV/AIDS clubs, maintaining self-development, and contributing to healthcare development.

Participants told the stories of attempting to seek healthcare and support in the community. They tried to seek support and treatment by disclosing themselves in the community where there were HIV/AIDS clubs. After they applied to be members of HIV/AIDS clubs in each district, they could access to a lot of resources. They described about the benefits of being an AIDS Club member at their nearby health setting. This club cooperated with NGOs to establish helping funds. Not only treatment information but also persons with HIV/AIDS would have a chance to join the anti-retroviral therapy project and receive many supports as in the following stories:

2.1 Gaining self-esteem, gaining self-responsibility

Most of the participants who could access the healthcare system had self-esteem and self-responsibility for their lives. Thus, they tried to seek for healthcare and treatment. Although they suffered from HIV infection which was life threatening, they had their will to be alive for themselves and family.

Ploy, a 32-year-old-widow, expressed how she gained her self-esteem and responsibility to be alive as follows:

When I had learned I had HIV infection, I was very sad. I thought AIDS was a very terrible disease. I thought I would die in 2 years. I was very frightened with AIDS. I thought of killing myself, so I took insecticide. But I was lucky... I did not die because my relative took me to the hospital. After I survived, I would like to stay alive for my kids. I had the responsibility to take care of my kids, my old father, and mother. I tried to go to the hospital to get anti-viral drug to live long life.....

Fe3Pa2, 89-105/3

Kaew, 24 years old with one baby, said that she had her self-responsibility in seeking care. Now, she had pneumonia and skin infection, and she tried to receive treatment to survive and take care of her baby:

Now, I have willpower and hope. I don't think about AIDS as the serious things. I try to use mild acceptance by believing in the Buddhist doctrine. I don't think about any thing that gives me stress and anxiety. I have my responsibility for my baby. I hope to survive...I often go to the hospital to receive treatment for myself and baby. I always think about my baby. I want to live long for her.

Fe5Ra, 609-614/14

2.2. Meet family supports and networks

Participants described the factors that encouraged them to overcome suffering of illness which were family acceptance and tangible support of money for healthcare expense. Family members such as mothers and relatives also took care of them when they had a chronic illness and were unable to earn income. Their families had compassion and helped them do daily activity when they had side effects of anti-

retroviral drugs. In addition, families of HIV/AIDS established networks to support each other when they performed their role as caregivers at hospitals.

Samorn was both patient and AIDS caregiver who had to take care of her husband. Her husband had chronic illness and was unable to work. Her husband's family offered 8,000 Baht for her to spend on daily living and as extra expense for treatment. She expressed how kind her family was:

My husband's uncle and aunt gave us for a monthly income of 8,000 Baht. Sometimes, if the money paid for medication was not enough, I went to ask for extra money. I could not afford more money for the AIDS treatment because my husband's uncle and aunt gave me the half of AIDS drug to help me. Anyway, if they did not help us, we would not have any money to spend on food. I always thank them every time I receive money from them. Without them I will be very troubled....

Fe55B, 1316-1327 / 37

Participants did not have money for the expense of special investigations for treatment with the anti-retroviral medicines due to its high cost. Thus, only patients with HIV/AIDS who had family support could access the anti-retroviral treatment.

John, an HIV infected gay, described the good support from his family:

I am better than others because my mom better understands me. When I was sick and did not work, my mom gave money to me for the treatment of diarrhea. And she gave me many ten thousand Baht for living. When I get well and are able to work, I can have little money to spend on living but no money for anti-virus drug. Last week my mom asked me how much anti-viral drugs cost each month. And she told my brother to go to talk with the doctors at the hospital about the cost of AIDS treatment. Without my mom, I could not have money to pay for CD4+ test and viral load test. It is very expensive. It is nearly 4,000. I pay 3,800 with no discount anymore...My mom offered money for anti-viral drugs for 2 months. Afterward, I can apply for the free anti-viral project from this hospital....

M44B, 998-995/ 28

Family support was important in maintaining the ability of drug adherence when patients took anti-retroviral medicines at home. Suda, 32 years old with

HIV/AIDS, expressed how her mother helped her do daily living when she had side effects of anti-retroviral therapy at home.

At that time, when I started taking anti-viral drug, I had serious drug reaction. I felt dizzy and could not do anything. I felt like having a hangover. My mom cooked food for me. She took care of everything for me She took me to the toilet and watched over me. If I did not have my mom, I would have died already. She took care when I took drug. I didn't do anything only eating and sleeping.... The drug reaction happened only one day and one night, and I could get well. My mom told me to eat tamarind. There were a lot of sweet tamarinds in that season, so I got well. Without my mother, I could not have recovered...

Fe9Pa, 535-537,540-557/16

A participant who had opportunistic infection told the story about family support that helped him overcome TB:

At first, I did not take TB drugs. My brother pushed me to take drug because I felt hopeless and I did not need to take drugs. But my brother told me he would not leave me alone. We were relatives. He told me how he would feel if I died. Our relative would be sad because I was not a bad gay. If I was a bad gay, they would be happy if I died. I listened to him.... At that time, I had no way out....no one understood me. I got many problems. I was irritated. Then, I felt good after he talked to me. He understood me...I continued taking drugs and got well.

M2B, 226-232/ 7

Participants said that they could establish a good network of caregivers when they had to provide care for their AIDS relatives at hospitals. The support group of HIV/AIDS caregivers could enhance the understanding and exchange their duty among them. One participant talked about the sympathy she received from other AIDS caregivers:

Most of patients' relatives who had the same illness knew each other. They did not reject AIDS patients, but they helped each other. When they were busy, and could not come to the hospital, the others could take care of another patient instead. When my husband was ill, I got some support from the AIDS relative of another patient. We could share warm water, help each other. It was better to have the special AIDS ward for us. Another patient's relative got to know me. We helped each other to care for our patients....we could share our duty when one could not go to the hospital. We supported each other and felt

sympathy with each other...it was so good.

Fe1Sk, 709-718, 728-732 / 20

3. Accessing to HIV/AIDS clubs: A resource for special treatment and support

Day Care is established to provide special care for persons with HIV infection who do not have opportunistic infection such as tuberculosis. These services are provided for HIV/AIDS patients who disclose themselves to community. The service provisions offer information for persons with HIV/AIDS through counseling by healthcare providers. Persons with HIV/AIDS can gain knowledge about self-care practice and modify it in their daily life so that they can reduce stress and cope with problems. Furthermore, it encourages setting of HIV/AIDS clubs and self-help groups so that many persons with HIV/AIDS can have self-acceptance and access to treatment that leads them to a mutual understanding among persons with HIV/AIDS. Participants told the stories about the good benefits of Day Care services as follows:

3.1. Ability to access quality healthcare and support to meet needs

In the north of Thailand, widowed participants told the story of seeking healthcare and support in the community. They applied to be members of many AIDS clubs in the healthcare center in their community. They could receive both social supports for their family and take part in a treatment project. Noi described the benefits of support like this:

In 2000, my lungs were infected, so I continued to receive drugs. This year I've joined this project since May...I take (anti-viral) drugs now. The project has announced that they have anti-viral drugs for members and let us apply to join and another club my friend urged me to apply for together is the With-Care Club at Mae Ra Rue (Phayao). ...This club was founded by Mercy House...It's very nice to join them. They offer a fund for children, too. My son has got one scholarship since kindergarten, for each semester, sometimes each year...about 1,500 Baht a year.

Fe6Pa, 274-314/7

Some participants who were new mothers become members of an AIDS Club in a hospital and received support from special services like Day Care. The support was about finance and powdered milk for baby in the first year. Fa is one of those who received the support, she said that:

I'm satisfied...When there's an HIV infected client, suppose that person is a new mom, they provide Day Care service for her. Those clubs support infected moms and give them willpower...canned milk support...They're called South Andaman Club. There're many projects such as the Call-On-Friends project to help those who suffer. In case of temporary aid, this project gives 1,000–3,000 Baht per person...Some funds were founded by the government. About the Call-On-Friends project's, NGOs has supported it. And the AIDS Fund has been supported by Welfare Office and Public Health.

Fe4Phu, 457-464/13

Orn was recommended from a healthcare provider to visit a Day Care service which provided a service for post partum HIV/AIDS mothers. She described the satisfaction with Day Care services. She had a chance to join group activities and gained much self-care knowledge.

The nurse at post delivery service who recommended me to go there told me that I would learn lots form a day care service. So, I decided to go there. It's better than staying home because I only has a little information from reading newspaper. I did not gain anything from reading so much. I met a kind nurse when I first went there, anyway. She suggested that I take some drugs (herbs). So, I take some herbs produced in hospital. I am okay. I am very impressed of the information she gave me such as how to take a good care of myself. I learned more about the drugs, what are good for me. I am glad that I went there, and thankful for the information I have gained!

Fe5Phu, 161-164/ 5, 165-168/ 6

Roong was satisfied with the Day Care service. She said that the health providers were friendly and paid attention to patients well. When sharing experience, they helped clients with HIV/AIDS to cope with loss and grief so that they could gain encouragement. Roong talked about the support from health providers in Day Care:

I am satisfied with the Day Care service. Some provinces do not have this kind of service. The health providers here take a very good care of members. The nurse who takes care of me is very kind. When there is a group counseling, the

nurses show their understanding to persons with HIV/AIDS. They know that we're all suffered. Some of my friends broke into tear and the nurses

comforted them. Everything here is just fine. I hope that there will be more nurses if there are more newcomers.

Fe2 Phu, 517-521 / 15, 523-524 /16

Some northeastern hospitals provided a Day Care service within the hospital.

The participants had a chance to do group activities. Many members advised and introduced more clients with HIV/AIDS to receive the services such as counseling that motivated them to access health services. A member of an HIV/AIDS club said:

I like to join the group. For the one who's first found out about his HIV/AIDS status, he cannot deal with the regret. He just stays home and isolates himself from society. I tell that person that there is a service for persons with HIV/AIDS.....he is not alone.....he can handle his situation. I think the service is useful for AIDS people. Some of them don't come here to get drugs, but they come here to find friends and to talk to someone. For example, the doctor may have an appointment in the next month, so the HIV/AIDS member just only meet with friends in the Day Care service. Some have only money to pay for a fare, so they just come. They need friends who have a mutual understanding. They can greatly release their stress!

Fe3Su, 195-203 /6

3.2.Accessing to special dental treatment and care

Participants who were members of an AIDS club in Bangkok could get the benefits of accessing reasonably priced dental care at a university healthcare setting. They could receive continuous oral care checkups and treatment such as fungal infection and dental care by dentists. They could have healthy oral and dental care and the information on how to prevent disease complication. John expressed his satisfaction with one governmental specific dental clinic:

I have used this dental service. The health providers wore the protection suits with safety caps, masks, and eyeglasses like a space man. That is a very clean clinic like an expensive one. The dentists were also polite, and provided good treatments. They said HIV patients should take care of their oral hygiene especially whose immune was less than 200...we could develop gum abscess, tooth cavity, and fungal infection of the tongue. So, I always check my oral condition and teeth and go to follow up at least 2 times per year.... The service

is not so expensive because they reduce the price for us if we don't have enough money to pay....

M3B, 655-661/ 18

3.3. Accessing home care for continuous HIV/AIDS care

Only seven chronic illness participants had experience in receiving home care from general hospitals and community hospitals. They told the story of effective home care that enhances them to regain health. Although home care is not established at all government settings, participants who received home care provided by nurses had continuous care and increased quality of life. Home healthcare made family and community accept persons with HIV/AIDS. They could gain the benefit for the improvement of their health especially opportunistic infection of TB and can recover more quickly. Some of them could return to work, while others could develop caregiver skill in taking care of their relatives with AIDS at home. The nurses who provide home care can motivate family and community acceptance of persons with HIV/AIDS.

Sai-jai, AIDS symptomatic with TB, described what she received from nurses and doctors who provided home care. She shared how important home care was to make community understand AIDS patients and recover from the illness:

When doctors did home visit, they explained everything to villagers. ...Villagers did not fear me or reject me. Nurses and foreign doctors went to visit my home. They brought a small pack of food for me once a month...There were a bottle of sweet syrup, dry food, dried-rice, a package of milk, Ovaltine, dried yellow, and green bean. They visited me twice a week. In my village, patients with TB whom they visited all recovered and became strong. For me, I am better... Doctors should visit patients who have severe illness like me, and take care of them at home...I want every patient to join the home care project...They (doctors) gave us a lot of good things.... They taught me to do activity such as doing exercise at home, eating good food to improve ourselves. Doctors always said 'drink a lot of water and do a little exercise for good health.' Doctors also gave very good mental support.

Fe11Su 275-390 / 9

Pim, a patient who had already been treated and overcome TB, informed about the effectiveness of home care service from NGOs named Medicines Sans Frontiers (MSF) nurses:

MSF called on me at home. The nurses told me that I was TB infected. They knew from my medicine, however, they didn't inform anybody in my family because they were afraid of my family's fear. They also taught me how to prevent myself from spreading it to the others. ...I avoided approaching my daughters when I had a cough or sneezing. MSF nurses gave me gloves and caring materials ...they helped me so much. When they visited my village, they taught the village leaders that it would be difficult to catch this disease. In fact they are the outsiders but they closely look after us. My family now understands me because of MSF help. People in the village do not object to me...

Fe8B, 62-69/ 3, 87-89/3

Samorn described her impression with the home care service of the nurses from a governmental hospital in Bangkok. She had skill training to be a caregiver in order that she could take care of her end-stage AIDS husband at home:

At least one or two visits per month... Nurses gave me a good suggestion. When I had problem and asked them, they could explain in more details than asking personnel at the hospital.... They were so calm. They kindly asked me about my husband's symptom. Can he talk?....Can he eat?.... Does he have fever or not?....How about drugs? ...things like that. They taught me how to calculate the calorie of a meal and how to add more nutritious diet... I had learnt to blend food and did N.G. tube feeding, when my husband symptom was getting worse, and he was unable to eat and had become very thin. These nurses were like the relatives who called on us. They talked to us modestly and made us feel like they were not only nurses but also the good healer....

Fe5B2, 1385-1399/38

3.4 Accessing to hospice care in community

There are a few hospices run by religion charity under the management of NGOs in different parts of Thailand. Persons with AIDS in the end stage who are homeless can have support for a shelter and hospice care. Two participants who were staying in Rayong told the stories of access to hospice care. They were in the end stage of AIDS with opportunistic infections like TB and PCP. They were poor, and had no

support from family caregivers and were homeless. Although they did not take anti-retroviral treatment in the shelter, they received the basic need supports for life survival. Participants could at least have a place to stay and receive basic needs such as food, and symptomatic medical care. Here is a story of a participant who could access to hospice care:

Ket was a 25-year-old woman whose husband left because he was not HIV infected. She lived with her own 7-year-old girl. Ket and her daughter were at the end stage of the disease. Ket could apply for staying in hospice care because she had low income and had no relative to take care of her. Ket and her daughter were getting better when they received care and support from Carmilion (NGOs) hospice, she expressed her gratitude:

Father Jon (the director of hospice) is very kind and polite. He never chases AIDS persons in Carmilion (shelter) away. People who want to be here have to line up for a long time to get into the care. I didn't know what to do. I just cried so much like I was nearly going to die. So, I could get into this place. I think that was because I have made a good merit in my past life. You know that it's not easy to be here. It's like heaven here. The people here take a very good care of me. I have good food. If we cannot take the drugs, someone will feed us. Although I cannot have the chance to take anti-viral drug, I am satisfied with the end of my life. My daughter is here, too. My daughter will have a chance to take anti-viral drugs because there is fund of anti-viral drug for children. Carmilion also provides educational fund. My daughter can study now.

Fe2 Ra, 519-523/ 15

4. Ability to maintain self-development

The factors influencing participants to have positive experiences in healthcare are the appropriate health information about treatment and self-care. Thus, participants could have ability to maintain self-development. Approximately 20% of the participants who profited from healthcare information could overcome the problems of their health related to HIV/AIDS. They could recover from chronic illnesses such as

tuberculosis, pneumonia (PCP) and fungal meningitis. They had determination to maintain their health, so they had self-care practice and self-monitoring as follows:

4.1. Performance of self-care and self-monitoring

As the anti-retroviral therapy project is limited, many persons with HIV/AIDS are not selected to participate in every health setting. Participants who were still healthy and did not want to have AIDS complications tried to seek health information to perform self-care and self-monitoring. Some participants had self-care practices such as doing exercise, eating herbal nutrition, and using alternative therapy including doing meditation.

A female participant who was still healthy tried to perform self-care regularly. She talked about her self-development:

I read every micro-biotic magazine. They said that the immune level will rise up after doing exercises. Morning jogging is better than evening jogging. I get up at 5:30 or 6 then go jogging around the park opposite Gwan-Phayao (Phayao reservoir) every morning. As for food, my special food is vegetables and milled-but-unpolished rice. After I went jogging everyday, I noticed that there were some changes. Previously, I had air allergy and flu but now I've never been sick with these symptoms, even during a rainy season or winter.

Fe3Pa, 298-304/8

The participants who had low immunity level and could not access to anti-retroviral therapy project tried to perform regular self-care activities. They were interested in doing activities that increased their immunity such as exercise and meditation. Most of them could have the development of their immunity level.

Nong was 44 years old with AIDS related symptoms. She used to take two combined anti-retroviral drugs, but she had drug resistance because her CD4⁺ cell counts declined to 55 cells/ μ l. She chose herbal medicine as her alternative treatment

after the one-year anti-retroviral therapy project was finished. Furthermore, she did exercise and meditation regularly. Her CD4+ cell counts were now 240 cells / μ l.

Herbal medical doctor suggested that I do exercises such as jogging and aerobic dance everyday. I love to do aerobic dance at home. I dance with my daughter. We dance everyday till I get sweat. The doctor also told me to do meditation, at least 15 minutes everyday. I am not very good at that. I always think of something else when I close my eyes. But I try! I do pray every night in front of my Buddha image. When I get seriously stressed, I listen to the music and drive around the city for relaxation. I always listen to the music at home when I am stressed.

Fe7Phu, 544-548/15, 549-554 /16

4.2. Ability to adhere to effective treatment project

There are some anti-retroviral therapy projects provided for a few persons with HIV/AIDS. Participants who had succeeded in qualifying for the anti-retroviral therapy (ART) project recounted their experiences in overcoming sufferings. Participants who had received anti-retroviral medicines during pregnancy expressed the good benefits of the projects because most of their children did not have HIV infection from them. Mothers with HIV/AIDS could maintain their health and hope for their children. They could have their choices about pregnancy.

Participants who had been pregnant discussed the good profits of anti-retroviral therapy at antenatal care. They received warm counseling that could reduce stress and promote hope for unwanted pregnancy. When they were in the program, they wanted to continue their pregnancy. A participant who applied for the anti-retroviral therapy project expressed that:

When I told a doctor that I want to have abortion, the doctor told me that there was a HIV/AIDS prevention program for pregnant women by taking AZT. It's only one out of three that the baby will get infected. That means two out of three will not be infected. He gave me a lot of mental support and encouragement ...He recommended me to go to a provincial hospital to get the treatment. He made an appointment to me to see him on the day he was on the shift. The doctor prescribed AZT for me when I was five months pregnant until I delivered the baby. He insisted

that I do exactly what he suggested me, like taking these pills on time and drinking lots of water

Fe5Phu, 69-76 / 3

There was the facility of anti-retroviral therapy projects for pregnant women in community and provincial healthcare settings. Participants who utilized antenatal service at healthcare settings could gain the benefit and were satisfied with this project. They received counseling on anti-retroviral therapy to prevent transmission of HIV from the mother to the child. This service offered hope to a mother to have a baby born with less chance of HIV/AIDS infection. A participant said:

There was a group counseling every Thursday. I came here often I never missed it. I came here when I was 4 months pregnant. I felt relieved.... I could talk to other pregnant women. We shared a mutual understanding. We hoped that our babies would be born without AIDS infection.... Anyway, I take only two pills a day, DDI, after breakfast. DDI will prevent my baby from getting the infection from me. I am very happy to be here. Some friends said to me like 'You look fresh and healthy.' That made me happy.

Fe4Su, 73-78/ 2, 86-88 /3

Participants who were selected to apply for anti-retroviral therapy projects had improvement in their health. Their efforts created the tolerance of side effects of drugs and modified behavior, and this adherence led to more effective treatment. They became healthy, recovered from the opportunistic infections, and were able to earn their living and support their family. The treatment under the anti-retroviral therapy project covered every treatment and testing expense. Participants, thus, reduced their expenditure and lived more comfortably even without family support.

Samart, a 36-year-old male, expressed how successful the anti-retroviral therapy project was when he applied for the 5-year-project in the hospital:

It's up to individuals. For me, I still felt dizzy when taking it, so I took it before sleeping. Why tolerate? I had no money to buy another kind of drug. I took what I've got. I took drug in order to get better than when I didn't take it. Maybe better since it's free-of-charge for CD4+ test (laughing) and for virus load test. After I joined this project, they tested my CD4+. It was increasing

from 60 to 180. In April, my virus load was 66. It's up to each one's consideration. We have a good and helpful project, so we should try. They gave a high regard to us. I don't mind if I am a guinea pig. ... I should try their drugs. They are responsible for the drug effect also.

M2B2, 441-447/13

A widowed participant told the researcher about the effectiveness of the anti-retroviral therapy that she had a better life after recovering from TB. When she had taken anti-retroviral drugs, CD4+ cell raised from 28 to 240 in one year:

AIDS patients should take anti-viral drug because it helps a lot. I, for example, have taken anti-viral drugs and I become better. I have an energy to work and earn money. I am not a burden on society. If not taking drug, I would just wait for death...I'm happy to be stronger...strong as I used to be. To tell you the truth, physical strength makes me wise. Like I know how to get a better life...anti-viral drugs is very important. I could have died since New Year unless I had taken the drug..

Fe8B2, 737-739/24

There was the distribution of anti-retroviral medicines to a community hospital nearby the participants' house in Phayao. A participant who was selected by hospitals and community committees described the new life she had after taking anti-retroviral medications for one year:

There are only six patients whom could join this anti viral project. I am one who is lucky. I take drugs and it is like I have a new life. Since I have received drugs, everything is good. I am never sick, I don't have opportunistic infection. I have self-confidence when I go everywhere because I am strong, have better looking skin. Before I had taken anti viral drug, I had a lot of pimples on my skin. It caused people to look at me and suspect when I go somewhere. Anti-viral drugs are very important for me. I take it and I feel better. I don't have any side effect. Six of us can return to work. They can earn money for families. I also can work and can take care of my parents,... my kids also.

Fe11Pa, 620-627, 637-639 / 17

5. Ability to be contributors to healthcare development

Contributors with HIV/AIDS were those who had overcome suffering in living or trouble in care and treatment. They intended to have access to health services and succeeded in the anti-retroviral therapy project. The majority of contributors were

healthy and able to present themselves as a role model to the others. Most of them were trained to be volunteers from AIDS clubs in healthcare settings and NGOs. Thus, they had the knowledge of HIV/AIDS treatment, and care. They worked as volunteers and the leaders of the network to improve healthcare system for their groups.

5.1.Volunteer to empower themselves and others

Participants who worked as volunteers always sought updated health information and participated in AIDS clubs' activities in order to bring back the knowledge to perform self-care management and give advice to their groups. Some of them worked as AIDS consultants via telephone or AIDS hotline and group support in AIDS club located in healthcare settings and NGOs. Some of them were trained to be volunteers and did home visits. As a result, they could gain empowerment for themselves and others.

Kob, 27 years old, with asymptomatic HIV, tried to participate in AIDS activities of conference and workshops. She said she gained a lot of knowledge and could be a consultant of AIDS clubs and worked as a volunteer:

I got the knowledge from conferences and group meetings. The resource persons were people who worked in the specialty area of AIDS. Some were doctors and some were nurses. For example, taking care of patients such as bed bath, I have learnt from nurses. I had training from the Thai Red Cross about taking care of patients at home twice and from other places. What place? There was any training I tried to approach and learned because I would like to have knowledge to apply for myself and I could also help others that is a very good benefit for me.....

Fe 3B, 369-383 /11

A female volunteer who had skill training from the hospital explained benefits of her duty:

Being a volunteer, I had gained knowledge and had a chance to help other patients to understand AIDS. At first, I joined the Candlelight Club, working there as a volunteer. Yes, I had a right to get a free-of-charge treatment at Bamrad Hospital...as a volunteer.....In my opinion, I don't want to forget what

I've learnt. I also need the new information. Especially I can meet new friends...I like it...we help each other...I become stronger...

Fe3B1, 386-395/ 17

Participants who worked as volunteers earned enough for a living and received the treatment welfare. Noom, a male volunteer, expressed how good it was to help others:

As a volunteer, my ultimate hope is to help the others...umm...I wish they could accept the truth as I can. So I work as a counselor. My duty is to make the newly AIDS infected persons understand AIDS and to give them willpower. I show empathy ...listen to them and give suggestions. ...I'm very happy to work as a consultant, so I keep on working.

M4Phu, 215-219/7

Nanta, a volunteer who did home visit for AIDS patients in the north of Thailand expressed how she felt worthy to be a volunteer:

I do home visiting on Monday to Friday. I go to (NGOs) Mercy office everyday. They do not force me to do. I work as a volunteer because I like to help AIDS patients..... When I do home visiting, I feel good. I am not stressed. I am happy to help my (AIDS) friends. My friends are worse than me....I give them advice from my experiences....I have my willingness to do this job. Although I receive a little reimbursement, I want to devote the last period of my life to benefit people and society as much as I can.

Fe8Pa, 947-950/16,1032-1033/ 17

5.2. Establish networking for group activity

Contributors who worked as health volunteers joined networks of other AIDS clubs and NGOs-related AIDS activities. They received the support in doing activities that served the need of their AIDS clubs. Some active contributors could create their own activities and receive the fund from NGOs and the government.

Mite, a 44-year-old representative of AIDS club in the southern part of Thailand, started the activity of his AIDS club and networking that enabled him to have empowerment to live for himself and others. He said:

I went to group conference at Kao-Lak. This meeting was managed by Rak Thai Foundation. They talked about the fund, so I presented the project of Call-On Friends. Because we had talked with our committees before went there, we could receive the money that we requested for. Not so much, only 50,000 (1250 \$U.S.) we used this fund to visit our friends at home. I have received these visits twice. It is very warm support, isn't it? Our friends have got to do many activities and many exchanges. We can form our group of ten as you have seen.

M3Phu, 233-236/8

Orn, who is a volunteer of AIDS activities, described her job in this AIDS member club. She refused to receive the reimbursement because the AIDS patients whom she visited were very poor and had severe illness. She talked about her group activities:

I do accounting for this Call-on project. We received the fund from Rak-Thai Fund. We used the fund to visit 120 persons with AIDS and gave them 250 Baht for each visit. The project covered only one year. The volunteer could receive money for the transportation for 100 Baht. Actually, it was not enough. It was very little money because the gasoline for car cost more than 100 Baht, but we did not need this reimbursement. We gave all of money to the patients whom we did visited. They were poorer than me. I met them and gave them all...

Fe51Phu, 698-699/22, 701-703, 705-711/ 22

In the northeast of Thailand, there were many AIDS groups established under support of NGOs and the government. They did activities of AIDS campaign resulting in the increasing number of persons with HIV/AIDS who disclosed their status and went to receive care at a provincial hospital and community hospitals. AIDS group members also received advice of health information and support from other NGOs. They were referred for further treatment and care at hospitals. Most AIDS patients could gain better health because of easy access to care.

Malee, an AIDS volunteer, talked about the AIDS group which helped a lot of patients with HIV/AIDS gain access to care:

Our committees have our own jobs. When in the seasons of working in farm, we work as farmer. After we finish our work, we go to join AIDS activities.

It 's better than staying at home. When we help others, we feel better. I have worked as a volunteer since 1995. We work very well. We've a lot of data of AIDS. Before this we did not have any data of them. I went to a village to campaign about AIDS. We have a lot of AIDS members with an increased number of disclosed AIDS people. They phoned to consult about treatment, or anti-viral drugs. I observed our members, at first if they did not disclose themselves, they were very sick, they were stressed. When they joined the clubs, they looked better. We have a lot of members and know that there are a lot of AIDS people in our province....

Fe31Su, 162-166/ 5

Participants who joined the NGOs program also disclosed themselves to public to promote the AIDS prevention campaign. A participant, Bauo, would like the young generation to protect themselves from AIDS infection. She described how she could develop her self-esteem to disclose herself to the public and speak for AIDS prevention:

I 'd like to speak to public to make people know how AIDS affects people. They did not know it. I 'd like to tell them when I had AIDS infection how suffered I was.... I firstly went to the district meeting hall. I was very frightened and feared the public.. As I got AIDS, I tried to tell people to know that it was not good to have AIDS ...I wanted them to see me as the real AIDS people. I trued to speak and answer their questions.... The last time, they invited me to a school to talk with students...I do not want them to have AIDS infection like me...

Fe51Su, 517-522 / 15

5.3. Collective groups to voice for improving healthcare

Contributors received support from NGOs and the government in their activities. They had a coordinating network with other AIDS groups around Thailand. Participants informed that they could access AIDS infected problems and understand their health needs after joining the activities and working as volunteers. Some participants joined the AIDS network in order to be a representative and voice for a new law. They demanded for cheaper anti-retroviral medicines and the right to gain access. A leader of AIDS club talked about group activities:

Network is more advantageous. If the AIDS infected persons hadn't established this aid network, only the government alone could not have helped us. That's why we have to help ourselves... We're now calling for Healthcare Act, still in the process... About anti-viral drugs, we're trying to found the Buyer Club. The AIDS Network of Thailand wants to establish a company to deal with the drug-distributing companies in order that we can buy the cheaper drugs for AIDS infected patients... also still in the process...

M4Phu, 1040-1045, 1050-1051/ 29

Num, an AIDS volunteer in the central of Thailand, discussed the activities of cooperation with AIDS NGOs and AIDS clubs to purchase the cheaper anti-retroviral medicines for persons with HIV/AIDS. She described the effectiveness of anti-retroviral therapy that improved the health of persons with HIV/AIDS:

I see a lot of people with AIDS who take anti-viral drugs and return to work. There are varieties of anti-viral drugs. Those who can access drugs have their permanent jobs, so they can buy the drugs. We (clubs) help them to cooperate with NGOs via Buyer Clubs to buy cheaper drugs for them. Now the price of drugs is cheaper than before. The triple drugs are about 3000, and the cheapest is a little more than 1000, but some people do not have any money to buy it... We talk with them whether they can afford the drugs... We have special doctors to checkup and prescribe drugs for them... Anyway, we hope that the government can help the poor to access free drugs...

Fe41Ra, 497-502/15

Some participants joined the networks of HIV/AIDS in order to be a representative of their group. They would like to advocate healthcare coverage for HIV/AIDS in the Healthcare Act and Regulation that is in the process of development. A participant who could gain access to the anti-retroviral therapy project from the north shared her activity when she went to do group collection in Bangkok:

Our groups and I went to Bangkok by bus. Our networks in the north came to join our groups from many plans in Thailand. I also volunteered to be in a group collection. There were many HIV people ... more than 10,000 people... I thought... We went to the government office to request for healthcare coverage of the 30-Baht gold card project. We wanted to voice for anti-viral drugs for AIDS patients. They should cover the anti-viral drugs in the 30-Baht gold card ... We had the support to travel to Bangkok by Japanese NGOs.....

Fe1Pa2, 735-749

Participation for needs and expectations in healthcare

Even though participants had both negative and positive experiences in access to healthcare service, all of them accepted those experiences as a lesson and became a representative in problem solving. Thus, they requested for a development of health and support service provision suitable for HIV/AIDS persons' need. The healthcare needs and expectation of persons of HIV/AIDS were described in terms of improvement of health service provision, increasing healthcare providers' capacities, sufficient community support, and resource allocation including developing healthcare policy and regulation as follows:

1. Improvement of health service provision

According to negative experience from service provision constraints, participants felt they were abandoned. Participants raised this problem for the improvement of counseling services in government and private healthcare settings. They needed health staff who did counseling and provided effective information in order to help people with HIV/AIDS understand and know how to deal with stress and hopelessness. Participants demanded that persons with HIV/AIDS need someone to put their faith in, give them courage, and understand AIDS. Nowadays there is no unit to respond to their needs and be the patients' consultant. Most participants raised their needs and expectations in access to health service provision in terms of health promotion and prevention of illness, quality of care and treatment, as well as continuum of care.

1.1 Needs of health promotion and illness prevention

Most participants who had suffering experiences after being informed of blood test results needed health information to maintain healthy lives. They needed

empathetic mental support and encouragement. They also needed specific information to promote their health and prevent illness, especially information of treatment in terms of anti-retroviral drugs. A participant suggested their needs for counseling services:

...I wish blood test center could give more advice so that I could have someone to listen and respond to my feeling... I wish... I think this support should be a continuing service, including giving courage. Now they don't give any courage and information on how to live with a good health. Furthermore, AIDS infected persons should know more about HIV infection. Everyone knows it's caused by sexual-transmission, blood transfusion, and drug addiction but don't know what HIV is...and how to cope with AIDS and prevent complications of AIDS...

M2Phu, 183-184/ 186-188 /6

What persons with HIV/AIDS infection needed after receiving blood-test result is the information of drug and treatment in order to get the suitable remedy from hospitals. They did not want to do hospital shopping and have blood test frequently. Nowadays the advice procedure emphasized prevention of AIDS infection more than AIDS treatment. Kum talked about the treatment information he needed from counseling:

They just informed me of the blood-test result and taught me how to prevent it a bit. However, they didn't tell me what the treatment and drug were about, where to get a checkup, how to protect things ... never told me... I also needed this information. If I got worse where I could find a right place to get treatment? ... No need to have blood test again. They asked about my wife, but not any suggestion given.

M1Su, 123-135/ 4

1.2 Health checkup and monitoring for early treatment

Participants who utilized counseling services talked about the inadequate service provision. Participants needed not only the remedy information, but also the health checking and the clients' health monitoring for immunity level. Most of them did not receive any health checkups and lost contact with health services. They came

to utilize health services only when they had symptoms. A participant suggested health check-ups from counseling service as follows:

At the time, I must confess I knew absolutely nothing. At least they (counselor) should have told me more. After talking with a consultant, he only asked me if I knew how to deal with my sickness. I said no. So, he told me to follow 10 primary rules of sanitation which I had learnt since I was a boy. He said that was enough so I agreed.... really.... The information I needed was about treatment and health monitoring. Those points were more important. I wanted to know how to check myself. I didn't want to get sick.

M4Phu, 122-126, 128-129/ 4

Boon, a participant with TB infection, needed health check-up services for asymptomatic HIV clients. He wanted to use specific services that emphasized health promotion and health check-ups. He also needed healthcare settings with enough public relations to promote patients to access treatment and care:

I think there're a lot of patients in remote provinces or remote districts who don't know that treatment can help them a lot. They don't know they should see a doctor and it's very important to come to the hospital. ...Doctors should give suggestion about diet and self-preservation for non-symptomatic clients.... They have to check themselves up frequently ...They should go to the hospital to do chest x-ray. For patients who have this disease (TB), they should have monthly checkup. Nowadays very few patients go to the hospital because they have no public relation to promote them to go to hospitals. Some patients have never known there is a treatment like this in the hospital....

M3Su, 661-667, 684-697/ 21

The participants who could access anti-retroviral projects reflected difficulty in asking for blood test for immunity level in their province. One participant raised the need for specific blood test for immunity level as it is important for monitoring her health status. However, this service was not available in provincial hospitals. Sufferers had to spend a lot of money on this service at private hospitals. She suggested the necessary test for immunity level as follows:

If it is possible, I would like the provincial hospital to provide the service of blood test for CD4 level. Because normally the poor and struggling patients

came to utilize healthcare services at provincial hospitals.... They did not have any opportunity to checkup for their CD4... If they wanted to check their immunity for CD4, they had to use the private hospital services that were very expensive... Where could the poor find the money for the blood test? If the provincial hospital provided this service for them and included in the public health welfare, it would help them a lot. They did not need to spend the money for CD4 test. So, they would have more money to spend on food to improve their health. I don't know when we will have this service in this hospital...

Fe1Phu, 641-644 / 19

1.3. Equality and quality anti-retroviral treatment and care

The main health problem of persons with HIV/AIDS was chronic illness. Although they continuously received the symptom treatment, they were not treated with anti-retroviral therapy (ART) because of the lack of money and healthcare coverage. Thus, the participants wanted more qualified and standardized treatment compared with others who were selected to receive anti-retroviral therapy.

Nop, an AIDS infected sufferer of TB, talked about the unfair treatment he gained from a healthcare setting. He needed more qualified and standardized treatment:

These volunteers used to be sick like me but now become better.... I think they have not only good willpower but also good drug made them better... different from me. Their drug must be very effective because each volunteer looks like normal people... Why? We're sick by the same disease but they don't have any symptom that I've got. Yes, I think like this. I wish treatment standard would be equal. Whichever good drug should be distributed to everyone... not that one gets that kind, this one gets this kind... expensive one, cheap one. Which drug has already been proved that it's good enough, let distribute or give it to us. I want this action... I also felt hurt when I didn't receive the (same) drug like others....

M1B, 756-711 / 21

Participants who had been selected to the anti-retroviral therapy project regained health and had normal living. They could work and earn their living for the family. All of the participants requested for anti-retroviral therapy for all patients with AIDS. They wanted their good experiences of receiving quality treatment to be equal for every AIDS patient. A female participant said:

The patients, who have symptoms such as herpes, weight loss, and fungal infection, should receive anti-viral drugs because I have these symptoms before. When I received the anti-viral drugs I got better, never had symptoms again. I want every patient who has AIDS symptoms to receive the same treatment like me, so they will not be sick. I need the government to provide anti-viral drugs for patients who are sick. If patients receive anti-viral drugs, they should give continuous drugs for them.... Don't say that the project was finished and no drugs were for them left...

Fe2Pa1, 469-475/11

The participants' needs and expectations for quality anti-retroviral therapy were congruent with healthcare providers' needs. The physicians who provided treatment and care for persons with HIV/AIDS suggested the medication for AIDS treatment:

I need the government to be concerned about patients with AIDS. I feel uncomfortable when they have to be treated with anti-retroviral drugs, but cannot help them to get the free anti-retroviral drugs. We do not prescribe anti-retroviral drugs for them because they do not have enough money to pay for the drugs by themselves. I think the government should consider AIDS as other chronic illness. The anti-retroviral drugs are cheaper than before because we can produce the cheap anti-retroviral medicines in our country. I think the basic formula of anti-retroviral drugs should be considered for the patients who have to be treated with anti-retroviral drugs.

D3/4-12/ 3

1.4 Distribution of standard care and treatment at community care

Persons with HIV/AIDS had health welfare to help them decrease the expenses of treatment and care in hospitals. However, they and family still had to afford the cost outside the healthcare system e.g. daily expenses, food expenses, traveling expenses, and care providers' expenses which all were high social costs. Some poor participants who lived in rural areas or another province far from a provincial hospital faced the difficulty in earning monthly income to pay for those expenditures in case they had to get the continuous remedy. They needed quality care and anti-retroviral therapy in the community hospital near their residences.

Lamduan, a participant with one child who suffered from PCP, had to take her son to the hospital twice a month. She wanted her nearby health service center to afford anti-retroviral therapy under the supervised provincial hospital every month. She suggested the specific care and treatment that community hospital should have:

Drug distribution service at Karbcheng Hospital (Community hospital) should be provided like that Surin Hospital (Provincial hospital). They should offer these 3 kinds of anti-viral drugs...in every community hospital. So, we don't have to travel to Muang District. ... We lost traveling expenses and wasted our time. At Surin Hospital, there were about 200-300 AIDS patients. So crowded and hot.... If there were a special treatment at Karbcheng Hospital, it would be better. Sometimes we missed the bus, so we had to stay or hire a car to go back home. I also paid for food costs. Child clients like my kid also got in trouble. If they get AZT and DDI drug at a nearby hospital, it would be better. In case of taking blood exam, or other difficult test, they must go to the hospital once every 3 months. If they did not have blood test, they could receive drugs here. Provincial hospitals should supervise community hospital doctors too...

Fe5Suk, 245-262 /7

Some participants mentioned the health service in community hospitals. Although they were satisfied with Day Care service, a lot of them wanted to get the same treatment as that offered at a provincial hospital. A 44-year-old male participant said:

It's nice to have group activity to advise how to live more happily. Once a month, I could meet other AIDS infected friends. We could talk and consult with each other about where to get treatment, what to eat. In Tha-Toom District, there were no health checkup services and special clinics like Surin Hospital. No drug project, no anti-viral drug. There's only drug to prevent lung infection. I want anti-viral drug for AIDS patients. In Tha-Toom, certainly there're about 52 persons with AIDS. More than half of them used to be fishermen. Now they've come back because they are sick and have no job. If they've got drugs, no need to travel for treatment in another place.

M2Suk, 57-69 / 3

A participant who worked as an AIDS volunteer asked for the continuous monitoring of anti-retroviral drugs to be provided in every community hospital. The patients in the nearby area should be taught about drug taking behavior:

The government should distribute anti-viral drugs to every community hospital. And they should train us to take care of our friends about taking drugs. I have assisted nurses to do this job before. About new anti-viral drugs given to clients, they should have special care because they are new to this drug. Some patients have just taken it for a month while some patients get drug allergic.... Another hospital arranged them every 2 months or every month. I think Jun (District) Hospital used to arrange a meeting every week. Those who took drug went there every week. Now each meeting is arranged every 2 weeks or every month. Only those who take this drug will come to receive advice or come to consult...It's near their houses. Every community hospital should offer anti-viral drugs now...

Fe2Pa1, 1072-1075/ 24, 1080-1082 /25

2. Quality treatment and care against discrimination

Due to bias and discrimination in treatment and care, when patients with AIDS were admitted in some health service settings e.g. Phuket and Surin, there still remained some problems from community acceptance and disgust. They wanted quality treatment and services equal to other clients' symptoms. They suggested the quality of treatment and care as follows:

2.1 Specific unit for quality HIV/AIDS care and treatment

Participants required a special ward for AIDS infection at hospitals in order to get rid of problems resulting from having to conceal their secret status to non-HIV clients and their relatives.

Nong talked about problems when persons with HIV/AIDS were not admitted at a hospital and the need to receive fair treatment as follows:

I want the doctor to give an intensive treatment for AIDS patients when they are sick at the hospital. Please don't think we are hopeless. I just want the same equal treatment as other patients with other diseases. Patients must receive suitable treatment. I don't want the doctor to discharge patients if they're still sick because it can cause problem that nobody takes care of them at home. Just wait till they can look after themselves. However, if there's no way to cure...please let them die in the hospital. Doctors shouldn't neglect them and should take care of them as much as they can.

Fe7Phu, 663-667/ 19

The end-stage patients asked the researcher to voice for them by telling their suffering experience to policy makers. They needed a special ward and treatment for persons with HIV/AIDS, as Boon-khum said:

If you persuade the government and they agree with our needs, it would be very good...Please tell them about my story. Don't forget about the special ward for AIDS's patients. I hope that Surin would be the central province of this part (Northeast)...Don't wait. There're lots of people with AIDS here. Please build the special building and directly select doctors and experts for us. Others know what illness we have, so it would be better to separate us from them... and take care of us at a special clinic. Don't forget that...If I died before everything happens, please make it for those who are still alive. Many teenagers are also asymptomatic AIDS infected. I've seen them in the group activity. They're afraid of waiting for treatment among the other sick clients because they don't disclose themselves....

M22Su, 732-737/21

Some participants who looked after their AIDS infected husbands also needed special wards for clients with HIV/AIDS because they would feel comfortable to live with follow sufferers of similar conditions:

I wish there would be a special ward for patients with AIDS ...so they wouldn't discriminate clients with AIDS. I need the whole ward for us-- for AIDS patients. Don't put us in the same room with other patients. No need to write on the building's wall that this is AIDS infected area...just let patients themselves and their relatives know. If the others know later on...that's OK...I don't know to keep a secret for what...

Fe7Phu, 668-673/ 19

The problems AIDS infected patients faced during their treatment in the hospital were about inadequate and inappropriate nutrition. Patients' relatives who were mostly their AIDS infected wives had to buy food for the patients while the care provider starved. A participant who was the patient's wife suggested that the hospitals have a special ward particularly build for AIDS patients. Thus, the hospitals can offer suitable diet for AIDS patients and help their relatives economize their expenses:

I've suggested to hospital executives that they should select appropriate diet of AIDS patients but they said it's impossible because there were several patients.

HIV infected volunteers in Day Care also helped us request for quality food... I want a special AIDS ward because they can select good and suitable food for us. I think poor quality foods are sweet, boiled rice, clear soup or spicy food...salted eggs, fried dried sea fish...the same cycle of menu. Some patients cannot eat this food. My husband is allergic to seafood, and he feels itchy. We have to buy other food for the patients and starve ourselves. We must manage our money. Being debtors means paying high interests. The hospital should offer more nutritious food like milk or fresh fruits. It's all up to the hospital's mercy. Sometimes we received unsuitable food so my husband got diarrhea and got worse. When we were home, he was still healthy because he got good food. When coming to the hospital in Surin, he had bad health....

Fe55Su, 663-680/ 19

2.2 Affordable safety family planning services for women

There were anti-retroviral therapy services for HIV infected mothers provided at government health settings ranging from community hospitals to provincial hospitals. This anti-retroviral therapy project was beneficial to HIV infected mothers because it decreased the HIV transmission from mothers to children and it was an alternative way for mother who wanted to keep their babies. However, mothers with HIV/AIDS would not be offered a legal abortion in hospitals. Four participants who had unwanted pregnancy informed that they were suffering and faced danger in having an illegal abortion at private health settings. Participants asked for safe family planning services for HIV/AIDS mothers who had economic problems and unwanted pregnancy.

Nid was suffering when being pushed to utilize illegal abortion because she had to lose lots of money and took a risk of dying from the abortion. Nid, thus, wanted this service to be offered to women with unwanted pregnancy.

In fact is it (abortion) should be provided here (hospital) because we must go to search for illegal abortion clinic..... We had to go to Chiang Rai at 6 a.m. and had to walk to find it (the abortion clinic) ...Instead of readily providing it, they let patients seek for abortion facilities themselves...I don't mean I didn't want the baby. I really needed it if I wasn't sick. It doesn't mean I'm cruel. I'm sick and lose willpower to take care of the baby. My health can't support childcare. My parents, grandpa, grandma, they're so old. My husband's parents

passed away. Our siblings have their own family. If the hospital has (abortion service), it'll be nice. Good for those who don't want the baby....no need to go to illegal abortion that is a dangerous service. For those who want the baby, they can take free anti-viral drug.

Fe7Pa, 144-146, 148 /4

2.3 Continuing care and effective referral networks

The participants requested for health services that included the care and therapy of persons with HIV/AIDS suffering from opportunistic infection like tuberculosis, fungal meningitis and pneumonia (PCP). They could learn about good experiences from participants who could access home care and effective care. Thus, they suggested for the continuity care and effective referral networks as follows:

2.3.1 Effective referral care and continuous treatment

Most of participants had suffered from receiving discontinuous healthcare services when they received counseling without information of treatment. They needed the healthcare providers to offer the effective referral services by facilitating the formal document to communicate with other healthcare settings that can deliver specific care for them. A participant who lived in the suburban area near Bangkok suggested the referral care for continuous treatment:

I need all health providers at anonymous counseling clinics to follow-up on all patients. They should send the letters to the patients to contact with the hospitals. They should ask them and offer the formal letters for them to receive the effective treatment at the specific hospitals, which are near their houses. They should help patients access the doctors and the hospitals that could provide care for them. So, you can know and follow up on all patients....And anonymous clinics should cooperate with the hospitals that they have referred the patients to....to receive treatment and follow the treatment they have...I think the patients need the treatment so much do not let them find treatment by using fate or make them hopeless to live....

M6Bkk1025-1031/28

Fah, HIV patients who worked as a health volunteer, described the discontinuous health service offered and the lack of monitoring system of HIV/AIDS patients at home. She suggested the referral system for home care:

I want the health staff to ask clients whether they want a call-on service or not. After they have been discharged from the hospital and perhaps they have moved to another province, there should be a letter to give them convenience to get the further remedy without starting at the beginning of the new remedy process. It depends on each patient to agree on it or not. It was not difficult because everyone loves oneself. They want to survive with self-preservation and live long. With sincere discussion, AIDS infected patients might agree with this method. Just talk to clients with mercy. All information is secret. Only Ministry of Public Health knows...

Fe4Phu, 901-904, 906-910, 913/ 26

2.3.2 Continuous home care to support clients and caregivers

Health services at hospitals emphasized only patients' care and lacked knowledge provided to relatives who were the caregivers. Participants who were caregivers could not provide specific care such as serious symptom observation and home care for family members with AIDS complications. Caregivers who were also persons with HIV/AIDS could not give care or observe exceptional symptoms owing to lack of caring knowledge. They did not receive any advice. Thus, patients with HIV/AIDS needed healthcare providers to visit them and suggest how their cousins could look after them without disgust.

Nop, a participant, described the experience as a caregiver of his severe-stage wife who had cryptococcal meningitis infection and tuberculosis. He told the story of caring for his wife without knowledge and did not transfer his wife to receive intensive care at the hospital. He felt sad when his wife passed away owing to receiving late treatment. He wanted healthcare providers to call on home to give care and teach relatives how to take care of patients:

Home visitors should be nurses or doctors visiting us... at that time we lacked courage. We didn't know whom we could consult. Relatives also lacked AIDS knowledge, so Call-On-Home service should be provided. I prefer nurses to doctors because they can give advice about care providing better. I watched over my wife without knowledge, just wiping her body or helped her take a bath. So, nurses and doctors should teach cousins or husband how to take care of patients at least one time every 1 or 2 weeks. We can't wait. This disease is more hazardous than ordinary sickness.

M1B, 592-605 / 17

So as to solve problems that patients with HIV/AIDS were objected to by cousins due to the lack of AIDS knowledge, the participants advised that if healthcare staff visited the patient's house, the relative would know more about AIDS and patient's home care and learn how to live with patients without disgust. Thus, all of them would have good mental health:

I want some healthcare staff to call on my house and teach them how to treat us and how to live together happily... teach some fools in my house to make them smart. If health staff comes, they will know more about how to care for me. I need them to explain and advise me and tell me about my symptom situations. Teach me how to take care of myself. Tell me the truth and teach my relatives about living together, about foodstuff. So, there would be no problem of disgust and mental health. The family members would keep a secret, stop advertising. It causes no good... My secret is just known in the family, my brother and mother.

M3B, 683-692 / 19

2.4 Continuing care to promote drug adherence

Problems about inability to access qualify treatment included the discontinuous drug-taking, drug allergy, or complications from adverse drug side effects owing to the lack of drug knowledge e.g. anti-tuberculosis drugs, anti-retroviral drugs, and opportunistic-infection drug.

Pim, a 26-year-old participant, said that she did not know the drug's name because it was written in English. She could not read, so she could not remember its name and side-effects. She requested for the Thai manual or drug description given to

persons with HIV/AIDS. In addition, doctors or healthcare staff should give advice about how to take drugs correctly:

They said this drug is the lungs' anti-infection and that's all. I read the label and took it... while I didn't know drug's name. It was written in English. It should be in Thai... It should be easier to read and understand what the drug is.... They should write the drug's name or its benefit on the label. Perhaps I want to know it in the future. At first they explained about side effects but now there're lots of patients... Sometimes, I forget easily about my drug information...perhaps due to side effects of drugs. They should give a manual or booklet. More advantageous...Perhaps I forget so I could read and know about side effects. They should offer some documents like this... but now there's nothing.

Fe3 SuK, 720-730/ 20

A participant, Parinya, had been TB infected but had already been cured. She talked about her experience of continuous drug intake that healthcare staff should give knowledge about drug and its impact. She stated that emphasized:

(Doctor) should give the explanation about drug use and when to quit the drug. ...Like me, I'm lucky that the doctor told me about side-effects while he didn't tell another clients. I worked here so I heard from friends that they didn't know it before. They were puzzled and worried about what would happen to them. They asked me if they had anti-TB drug and became bad. They were afraid of death. It didn't cause death...be patient... it would be better. I used to take this drug and confronted the same symptom. My lips and skin turned black. My hair fell down....This side effect would be better, be patient...

M2B, 337-345 / 10

People with HIV/AIDS who could access to anti-retroviral therapy but could not take medication continuously were worried about anti-retroviral adverse effects that could cause poor compliance. They needed persons with HIV/AIDS who were successful in anti-retroviral therapy to give them consultation. Somsri needed a group support when receiving medicine:

Neither others' words nor good services could help me since it happened to me myself. It took a lot of patient. So I wanted to meet other patients and looked whether they could be patient. Why if I can't stand it? Are they suffering as

me? So what I need are friends who also take anti-viral drug to exchange experience because I can't disclose myself to other normal people...

Fe6B, 276-279/9

From the experience with government health service, participants had realized the problems about clients' drug intake. They received knowledge that they did not understand. Thus, persons with AIDS needed clear explanation of medication. Nok, a volunteer, said:

When talking to clients, explain them using easy-to-understand words. There should be no technical terms or medical terms. I need normal and easy words ...Suppose we are talking about drugs, right? Drugs for clients should be explained about how to take them correctly. Now almost all who come just receive drugs and go back home. Some don't take it because they don't know. Doctors never told them they have to take it continuously. If not, there'll be drug resistance. No explanation and just let them go. They should ask nurses to explain them. This point hasn't been offered...until now...not at all...

Fe2Pa 1056- 1057, 1059-1062 / 24

3. Increasing healthcare providers' capacity

In the participants' opinion, the characteristics or quality of healthcare providers should be improved. The participants received the inadequate health services from provincial health settings that offered special treatment from experts. However, due to the overcrowded patients and inadequate health staff, the healthcare providers had no time to give explanation and health information as participants needed, while at the nearby health service centers, staff did not have updated AIDS information to give advice even though they were friendly and kind. Furthermore, participants had noticed that doctors who did not run the anti-retroviral therapy project provided the low standard treatment compared with those who ran the project or experts. They described healthcare providers they needed in terms of adequate qualified specialists and experts in HIV/AIDS including healthcare providers who needed to be accredited

for qualification. They exemplified the characteristics of healthcare providers as follows:

3.1 Qualified and adequate specialists in HIV/AIDS

The participants needed the healthcare providers who had specific and updated knowledge of HIV/AIDS. There should be enough healthcare providers like doctors to provide treatment and care for persons with HIV/ AIDS. They described the characteristics of care providers they wanted that health service providers should have updated knowledge of HIV/AIDS, be friendly, and live near their areas:

A counselor should be a nurse or a health center staff who knows a lot. If possible, we would feel warm and close to them as we were living in the same area and we felt comfortable to talk with them. But in reality, they have for us no time to consult. Officers of health centers mostly are nurses. Some have knowledge but not as much as doctors or experts...In fact they know just a little bit. And....like...not updated...like that. What they know is just the old information that everybody's already known. They have the same knowledge level as I do. They have to keep abreast with new drugs or treatment. They should know the newest and sufficient information...know there is about treatment news so that they could tell clients. Must tell clients... Nowadays no nurses... like that at the health centers....

M3Su, 96-99, 104-114/ 4

Kampon, a 32-year-old symptomatic AIDS patient, described his experiences of healthcare. He pointed out that there were a lot of patients with HIV/AIDS while there were inadequate doctors resulting in unqualified treatment. He needed the proficient doctors, and the hospitals should provide enough doctors with adequate quality treatment:

Thai doctors had plain diagnoses and treatment. Frankly, they hurriedly diagnose patients. Sometimes it was like they were working in a stunned manner... may be there were a lot of clients. Their own schedule was half-day working only. I don't know they spent their time on what. Arrived at the OPD at 2 p.m. like this, no morning treatment here. They worked for very short time in a day. Clients had to wait for so long. Wish they would work ...wholeheartedly... Yah! In case not enough staff, they should have asked for more. Not like now. Let patients wait for them. Some old patient's were very

poor. Some were laid on the bed waiting for doctors and cried all day until getting drug. About treatment, it should be faster so patients wouldn't have to wait. It's so boring that patients don't want to go to the hospital. Must be fast but qualified diagnoses and treatment. Some can't go back home as they missed due to missing village bus which can only once or twice a day.

M2Su, 564-587 / 18

Most of the participants who suffered from opportunistic infections needed the improvement of healthcare providers. They needed the healthcare providers who were experts in HIV/AIDS so that they could receive the standard treatment that prevented opportunistic infection in the early stage of the disease. A member of HIV clubs said:

If persons with AIDS had CD four less than 200, some general doctors who did not have the special knowledge about AIDS would not provide the drugs to prevent opportunistic infection to them.... We need doctors or nurses who have specific knowledge to treat us... The drugs that prevent lung abscess is not expensive, only two baht a day. I think every governmental hospital should provide the prophylaxis drugs to us because it was safer than to treat us when we are sick. We should not die from the complication disease that we can prevent ...

M3Phu, 1048-1250/ 16,132-134/ 21

The participants' healthcare needs and expectations were congruent with the needs to improve capacities of healthcare providers who provided treatment and care at community settings. They asked for the improvement of their skill in treatment and care.

The community hospital has only one doctor.... when the AIDS patients come to visit the doctor,...they rarely meet the doctor... Only two nurses provide comprehensive care for them... We do a lot of services such counseling, mental health, drug addicts ...but we do not have enough knowledge and authority to prescribe the treatment and care... We don't expected that we have to do the treatment role.... it is the treatment roles that we do not have the special license. If we made some mistakes, the [Nursing] council could not help us. We need the formal job description from the director. We need to improve our skill in AIDS treatment and care because we do routine care everyday and do not get updated education. We are afraid that we do not pass the board examination because we are too old and never have continuing study...

FN, Pha1-15 /2

3.2 Accreditation and quality of private healthcare providers

Participants who had the Social Security scheme and utilized healthcare services at private health sectors had met unqualified healthcare personnel.

Consequences of ineffective counseling caused them to deny treatment and suffer.

They needed the Social Security Welfare Department to monitor the quality of health personnel and service provision in private sectors. They also needed health personnel to improve their knowledge about AIDS and be able to provide adequate information for them and their family.

Malee, TB infected and recovered, asked for qualified doctors in private health sectors:

Private hospitals had one weak point about the doctors who worked there. They did not have enough knowledge about AIDS. Doctors who treated me told my family that I would die after being discharged in April (1998). But I could live until now. He misdiagnosed me, and he must not predict the death time for AIDS patients. He had better advise family to take care of patients or teach how to live with AIDS patients and take them to cure. But he told my family about my bad side. He told I would spread TB and AIDS to family members. He should tell me to protect others from getting infected instead. My family members were rural people, under educated, and they didn't know much about AIDS. What doctors told them, they all believed the bad side of AIDS patients. Instead of taking care of me, they objected to me and avoided me because the doctors did not explain to my family how to support the patient's mental health and take care of them correctly...I want private doctors to improve their knowledge.

Fe2su, 264-266, 268-275, 279-284 / 8

The participants who had the social security card and suffered when utilizing the private health sector suggested the Social Security Welfare Department monitor the qualification of the hospital and staff. A participant who had fungal infection lost follow-ups and did not receive continuous treatment from the private hospital said:

I wanted the Social Welfare Department to investigate and monitor the quality of the private hospital. If hospitals are not qualified, do not allow them to treat

patients. Social Welfare Department should not give them the license. The doctor did not care for me when I had severe pain. I was very hurt. He gave me only painkillers. They did not investigate or check my symptoms seriously.

Fe1B, 83-86/3

4. Community support and resource allocation for healthcare

As the HIV/AIDS clubs were established in provincial hospitals and Bangkok hospitals, persons with HIV/AIDS could access them to update on AIDS information of treatment and care. In each month, some volunteers from AIDS contributor group would be a representative of positive health and assist the health staff to give advice and be a consultant in healthcare services. Contributors with HIV/AIDS who were satisfied with Day Care services were willing to participate in Day Care services in every community healthcare setting. They needed community support to distribute Day Care and AIDS clubs in community healthcare, support for end-stage care, allocate the resources to support children, and sustain occupational support.

4.1 Distributing Day Care and AIDS clubs in community healthcare

From participants' experience, they worked as volunteers in healthcare settings and knew the impacts of inadequate Day Care at other healthcare centers in the provinces. Nong was the president of a provincial hospital's AIDS Club. She joined Day Care activity that encouraged persons with HIV/AIDS to participate in care. As a result, a lot of persons with HIV/AIDS would be promoted to access care by their group support. She suggested that Day Care should be provided in every healthcare setting in the community:

Day care should be provided in every provincial hospital and health centers. Each place, each group is still better. Last month I went to Krabi provincial public health office...I told them I'm the president of South... Club and I am also people with HIV/AIDS. They were very happy and asked me to help them. They couldn't access local villagers around Khao Phanom District.

Nobody dared to arrange mobile service units to give health services there. They need my help to give those villagers HIV knowledge. It sounds like there's no group in Krabi now. In the remote villages, there're lots of AIDS people who don't know about self-preservation. People in community are the same. Other villagers object to those persons with AIDS like they have had unsuitable sexual behavior. Social acceptance is still bad.

Fe2Phu, 406-413/12

4.2 Need for continuous care and acceptance from family and community

Almost all of the participants were worried about their sickness in their end-stage illness. Participants who lived in the province where there were a lot of AIDS patients and epidemics such as Phayao had seen their relatives and husband die at home without home care from healthcare providers. Almost all of the participants needed and hoped to receive quality end-stage care at home. They also wanted healthcare staff to call on them and provide home care. A participant said:

Most of AIDS patients died because they did not receive the quality and effective care. They were left to die at home...Family did not care for them well because they didn't have enough money to afford good food to eat as doctors suggested. They didn't know how to care for their relatives. It was very difficult for us...I needed doctors to visit us at home...The doctors should bring us the food, give advice, give medicine to relieve pain. The doctors should know and get close to us. I needed them to visit our house to investigate and see why we did not get well... They should know...

M4 B1, 692-700/20

In the province that Nong lived, when reaching the end-stage of AIDS, she wanted AIDS patients to receive treatment in the hospital like her husband did. That was because there was no hospice care setting in Phuket. Other settings were far and difficult to travel to, as she lamented:

I have seen my cousin-friend die at home. His relatives abandoned him. It was nice for my husband that he died at hospital. Doctors didn't oust him to come back home while a cousin wasn't admitted by the hospital. He didn't die in the hospital because doctor knew he couldn't recover so he just received drugs to take at home. ...But those who don't have relatives might be disgusted. Some persons object to persons with AIDS so much that they don't allow AIDS

patients come into their house....If they want to go to the temple, temples are very far, too. Bhuddhabat Namphu (Saraburi) is too far to go. In Pang-nga, there's a place (for end-stage patients to rest till die.) but few patients go there...I saw a few places in the south.

Fe2Phu, 488-491, 493-496, 498-499/14

Clients with AIDS who lived in the northeastern and central parts of Thailand still had problems due to the lack of community acceptance and place for end-stage care. Some of them were widows and stayed with old relatives. Participants needed family and community acceptance to support them until the end-stage of the disease.

Malee, a widow living with an old mother, suggested that the government should provide more end-stage care settings as follows:

There should be a place to give end-stage care. In case of serious condition, patients should consider it. If family understands them, that's the best. There are a lot of patients who don't have family but they are very patient to take care of themselves. They tried their best no matter what happened...They could be patient till they couldn't bear it anymore. ...This is a very severe problem of AIDS homeless people occurring. I've joined it for 1-2 years and I felt the patients increased. Family didn't accept them. Community doesn't accept it so where can they live? It should be a prepared place offered for those who don't have relatives to support in community.

Fe2Su, 555-566/ 17

Nowadays persons with HIV/AIDS are still not accepted in society. For instance, in some sensitive areas like the south, the northeast, and the center of Thailand, participants face with objection from community. They need the government's public relations to campaign for better understanding and acceptance of people with HIV/AIDS.

Noom, an HIV/AIDS representative, said that the community's acceptance and disgust problems were caused by the fact that the government did not have the campaign on the knowledge and understanding to the general public. He suggested that the government promote the right knowledge in order that the public will accept and let persons with AIDS live with the community.

Community acceptance is very important for us. First, it should be the AIDS education given to the community. Now the people in community have very little knowledge about this disease. Some have little to extremely little knowledge. ...The community believed in what the government had promoted such as advertising or things like that. I wish they would advertise the human right that...umm...persons with AIDS are also humans. We can live in the same society without discrimination....I think the first thing to do is to give AIDS education to people in community because they won't understand it if they don't have better knowledge and education. If we bring about community knowledge, persons with AIDS and their family will be able to live in community.

M4Phu, 583-591/ 17

4.3 Support and care for HIV/AIDS' s children and caregivers

In provinces of the Northeast, South, and Central regions, there is a problem of community objection that affects children whose parents have HIV/AIDS. Thus, they could not receive support and be impeded from access to beneficial resources in the community such as entering school and receiving scholarships. Both HIV infected children and non-HIV infected children lack those who they can rely on because their parents have died and relatives have low income. The number of orphans is increasing and becomes society problems. The participants wanted the government to deal with the impacts of HIV/AIDS on orphans immediately.

From the experience as an AIDS volunteer, Paka talked about impacts that AIDS orphans were objected by community and needed help from the government as follows:

...I want to suggest about the scholarship for children whose parents are AIDS infected after their parents die. Nowadays It is a crisis problem that a lot of these children aren't accepted by schools in Surin...At Sangkla (District), Nern Sa-bai Village is also faced the same problem. The villagers don't want that boy to go to school and forbid him from playing with their children. They're afraid of AIDS infection. Now this boy is in the hospital. We picked him up for treatment. He's very poor. I hope children whose parents are AIDS persons would be able to go to school without having to face disgust because they're not wrong. They

received the disease from their parents. The government should offer scholarships to these children because now they do not receive enough help.

Fe4Su, 828-832/ 24, 834-836 / 25

Moreover, another problem found in orphans whose parents died of AIDS is that they become burden of the old relatives who are caregivers. Participants from the South wanted the government to give them help in orphan care:

These orphans are very poor...very pathetic, I think. This problem is increasing. The government should be able to help them. Their relatives, I think, should receive financial help in this matter. I think it's not certain that they would become persons who bring benefit to society or the country. We don't know the future of them. To be a good citizen is the most important. They should receive scholarship to further their education. Or, yes, the government should take care of them. Although they live with their grandparents or cousins, the government should not let them be a family burden. They would be social burden. I think if we help them grow up in the right way, I mean orphans, they would be good citizens of society.

M4 Phu, 644-649/ 18, 650-655/ 19

4.4 Continuous support and sustainable occupation needs

Government fund arrangement for HIV/AIDS support from Public

Welfare Department or related sectors in the Ministry of Labor and Social Welfare was very advantageous to people with HIV/AIDS. They could use the fund as an occupational capital when they are unemployed. Nevertheless, almost all persons with HIV/AIDS used to be laborers and never worked as agricultural workers. They lacked animal feeding knowledge and never knew what animals could cause the opportunistic infection. Moreover, the government did not provide officers to monitor or arrange skill training for occupational causes. As a result, persons with HIV/AIDS gained no profit or did not earn more income. All participants wanted the government officials to provide occupational training and to monitor fund results.

As in the case of Dokmai, she had asymptomatic AIDS infection and looked after her husband who had fungal meningitis. She talked about occupational

investment and the loss due to the lack of investment knowledge. Dokmai needed the government to teach or give occupational advice as follows:

In fact, agriculture experts should have taught us how to feed animals and about the kinds of animal we should feed. For AIDS persons, we can't feed winged animal because we can get more fungus from duck and chicken easily. But nobody told us about fungus infection by winged animal feeding. They should suggest us what job we can do and what job is risky and the reason...I should have fed pigs. There're lots of sufferers as me...lots of them...but almost all are still alive... The Fund was all gone with the ducks. I got rice. I gave it to ducks. I sold the rice and earned 400-500 Baht...I bought food for ducks. All gone....both rice and animal food...gone with the ducks. I've received about 2,000 in return. Invested 8,500 but gained 2,500...I lost 5,000....

Fe5Su, 615-616 / 17, 618-626 /

5. Improvement of health regulation and policy

Participants who had both positive and negative experiences in healthcare systems had already known that their rights in health policy and some legislation blocked their access to healthcare. They requested for the improvement of the policy as follows:

5.1. Consumer protection for quality alternative therapy

Almost all participants who did not receive anti-retroviral therapy said it was because they had no money to buy costly anti-retroviral drugs. In addition, some participants had tried anti-retroviral therapy and faced adverse drug effects, so they had to leave the anti-retroviral therapy project. About 85% of the participants had experience with screening for alternative treatment such as taking herbal drugs from traditional Thai doctors or monk doctors at some temples. Some had tried herbal therapy whose properties were in AIDS treatment, but they did not gain the effective treatment. Participants wanted the government to approve the properties of the herbs and found herbal drug projects just like the anti-retroviral therapy project. Nong, a representative of an AIDS club in the south, suggested scientific methods of alternative therapy:

Some patients couldn't take anti-viral drugs. They had the intervening symptoms after taking them, so they had to stop. Like what happened in my project. Only 7 were left from the total of 20, while the others had to return their drugs. They couldn't take it due to intervening symptom, so they turned to herbal drugs or nothing at all in some cases. They kept up their health in traditional ways, just doing exercise and having normal foodstuff. But the good choice is herb. Herbal drug is very important. It's natural. I want the government to arrange budget and encourage herbal drug use more. I want them to establish the herbal project to do research on herbs that can kill virus or stop the virus growth. At least it could prolong persons with AIDS life. Furthermore, herbs are not harmful and a lot cheaper than anti-retroviral drugs.

Fe2Phu700-707/ 20

Samorn and her husband were short of money to buy anti-retroviral drugs so they took herbal drugs instead. She described her experience of being fooled by a drug advertisement as her symptom did not recover after taking the drugs. She went to Chashengshao Province to receive the drug about 5-6 times, and she saw a lot of AIDS patients who came from many provinces receive expensive and unfair service charges. Samorn wanted the government to control V-1 drug use in order to prevent people from being taken advantage of or having to pay too high the costs.

Since April (2001), it had been advertised. I've been there 5-6 times. First they gave me a little so I went again. I waited for a long time in the long queue. ... About 1,000 clients waited for drug distribution. (I've met) a patient from the North who donated little money and received ten or more pills. I asked her why she didn't ask for more since she took a long time to travel. She said she had not much money if they gave her a half of the pills, she would receive only that half dose. Compared with me, ... She came from Phayao... I doubted why the Ministry of Public Health had allowed V-1 drug to be advertised like that. In my opinion, I don't understand why it has the uncertain formula. Why was they allowed to do this? They denied disclosing the drug formula and we can't do anything to force them to tell us... it should be controlled by Food and Drug Organization. Like V-1, there's no assurance but more than 1,000 patients have already taken it each day. In fact I'm not sure how much we should take it in order to make it effective. But what is it? Those who have little money take it in little quantity. Will they recover? I don't understand. They cheat and rob the money from the poor patients who have no hope for anti-viral treatment. Why did the government let them do this.

Fe5 B, 695-703/ 20, 721-724/ 21

5.2 Healthy and health promotion coverage for workers

Eighty percent of the participants used to work as laborers. Some of them never knew about their rights and the support they should receive when they were sick. Some participants left their job suddenly because they were afraid of being objected by colleagues. So, they missed the advantages they should have gained from the social security fund. Although they used to pay for the fund, they stopped paying after leaving jobs. As a result, participants who used to be employees could not use social security rights. They suggested for their needs as follows:

5.2.1 Need for health information to access health welfare right

Participants who had AIDS complication and got opportunistic infection reported on their experience that they did not get information of their rights in health welfare, especially the social security card. Thus, they did not know how to negotiate or request for better support and services from healthcare institutes. Some participants suffered from early discharge and did not get enough support from the health welfare.

Ann had chronic fungal meningitis. She told her experience when admitted in the hospital. She had early discharge to utilize Day Care services, and she did not know how to seek compensation from social welfare. She needed health staff and social security units to inform her of the right in healthcare:

I didn't know how long I could stay in the hospital. I was always admitted for only one week. The doctor let me go home and receive fungal drug at Day Care, so I must go. I used social security card, right? I don't know...whatever right I have, I don't know. Nobody tells me about my rights. Laborers who have social security should have been explained about their right. I needed to know about financial support if I was sick. Would I receive my money after quitting the job? When I was sick, how much would they give me money? I needed money for investment and wanted to know about the right to get treatment. During my stay in the hospital, I knew nothing. Doctor said 'you're alright,' so I thought I was alright. I didn't know how to explain it and what to do although I was still ill. They let me go back so I had to go back...and come back to the hospital again. I had to come and receive anti-fungal drug... so

suffering...I could not work. How could I have money for travelling and buying food...?

Fe1, 77-96/ 48

The restrictions of social security welfare did not cover the cost of routine health check-up which was one method to promote health and prevent illness for laborers. In addition, service provision at factories was neither adequate nor appropriate for laborers. Participants who had been laborers in factories claimed that there was still AIDS discrimination and laborers being rejected when they were known as AIDS infected persons. Participants called for the Ministry of Health to monitor closely to promote healthy workers. Health services should be provided in factories especially information of AIDS to maintain health of workers in the workplace:

There should be health services in the factories like information of self-care because there is only a small nursing clinic. There should be x-ray, blood test, health checkups for workers every year. In my factory, we have blood test every year, but I do not know why they took our blood test. They should give us health information or cure us if we have health problems. There should be doctors or nurses in nursing clinic for 24 hours. Doctors and nurses should have knowledge and give us health information, especially AIDS. I have got severe illness of TB though I have never been negligent of my health. I don't have any knowledge of any diseases, and I don't know what AIDS is. It (AIDS) does not come to me, so I am not interested in it. The company should have a clinic for take care of persons with HIV infection, so they will have self-care information to care for themselves. Why did the company check drug addiction from urine? When they know who are drug addicts, they lay off them. When workers have HIV infection and illness, they also lay them off. I have seen workers who are AIDS infected were laid off.

Fe1Su, 760-770/ 22

5.2.2 Fair reimbursement and prolonged support

According to participants who used to be laborers, they had to leave for their jobs due to the sickness, so they had no income. They also lost the right to receive money that they paid for the Social Security Fund back then because they did not pay the next installment. They needed fair reimbursement from the money that they had paid for the Social Security Fund.

As an employee who had to pay for the Social Security Fund every month, Orn wanted the re-payment of the allowance for employees who had to pay their salary to the Social Security Welfare. Almost all persons with HIV/AIDS who left their job before time would not have a chance to receive their money from this fund as they could not continuously pay installments:

Aid from Social Security is offered, but not enough. In fact they should return to us the same as what we've paid for...Umm... I need a welfare that creates fund for jobless or retire persons. We should receive things like that. Like the government' pension. However, nothing's like this for Social Security Fund payers. Some have to pay for 15 years, or more than 10 years, while their lifetime is shorter than that. Some quit their job in 4-5 years and lose their money in social security fund.

Fe5Phu, 447-454/ 14

5.3 Universal healthcare coverage for prevention of illness

What every person with HIV/AIDS needed was the health welfare which covers anti-retroviral therapy in order that they would receive the quality treatment, leading to better health and long life to work and to look after their young children. Participants needed anti-retroviral therapy for prevention and protection of opportunistic infections. As a result, they wanted the government to enact the health policy for anti-retroviral therapy coverage. However, many participants felt that they were worthless and understood that the government gave them unfair treatment because they were condemned as the wrong-doing persons. Pim, 25 years old, expressed her feeling and her need for treatment equal to persons with other chronic diseases:

If 30-Baht card plus anti-viral drug... it sounds selfish. Government thinks we have gained a lot. We receive free-of-charge treatment for TB and fungus infection. Now anti-viral drug costs about 1,000 Baht but we cannot afford it by ourselves....Heart disease and Diabetes...even their drugs are very expensive but government give the drugs to them. Those diseases can't be

prevented...They suddenly occur especially in old age. But we can prevent ourselves from these infection diseases... It's my false...the young AIDS infected, as I can't earn myself. The government should treat the young patients before letting them die. ...Our children are not wrong. ...The government should treat young AIDS patients. ... If I didn't have my child, I wouldn't come to hospital to receive treatment but I want to survive for my baby ...Die today or tomorrow is the same, I think.

Fe5Ra, 989-997/23 1023-1025/24

Samorn, an AIDS symptomatic patient who also got worse by PCP opportunistic infection, had to take care of a sick husband who got brain fungus infection and was bed-ridden. Both of them had been treated without receiving anti-retroviral therapy and still had chronic illnesses. She advised the government to support the spouse who was stronger in terms of drug expenses. She suggested the treatment of anti-retroviral therapy for persons with HIV/AIDS to maintain a healthy life:

Anti-viral drug... though costly, they should offer it to us. If they help only me, it means they help my whole family. Don't you think so? If I become better, I would be able to take care of my family and not be Buddhabat Nampu (Temple)'s burden... Although one in family gets worse, the others are still not. I can take care of children. This problem will be decreased if every AIDS infected family receives this aid. Suppose my husband became better after taking the drug, he could come back to work in his family's store. His family doesn't object to him. Now I still don't have it because I'm not sure. The doctor did not explain much to help me. If my husband had taken it, he would have been healthy enough to work, I would have paid the doctors. My family would have been together... we wouldn't have been social burden like we are nowadays...

Fe5B,1580-1593/ 45

Amorn, 35 years old, told about her experience that she had suffered from TB and infected lungs. She had to be admitted into the hospital and receive financial aid from the hospital's social welfare more than 50,000- 80,000 Baht for each treatment. During that time, she became a family burden. After applying for the anti-retroviral

therapy, Amorn became better and healthy enough to work. She compared the cost of opportunistic infection treatment that was higher than the cost of anti-retroviral drugs:

Those who have low income should have 30-Baht card. Poor AIDS patients should receive free-of-charge cost while rich patients should pay more than 30 Baht. The rich should help the government more. Those who have money should pay for anti-viral drug. I think they can afford it if it costs less than 2000 a month and poor patients like me are still not able to. I would try hard... I think I can find 500 per month to pay for it..... In fact 2000 per month is costly for the poor. The government shouldn't have excluded that AIDS from 30-Baht card. Should give them remedy when they're still not worse. Like me, I have been sick with TB, and my lungs were infected. It costs me a lot because I was always sick, admitted so many times till I was unable to work and became the family's burden. Now, I've got anti-viral drug and become better and I can go back to work to work. I'm now able to look after my children.

Fe8B, 1327-1334/ 39

Participants who used their social security right and were still healthy enough to work wanted the Social Security Welfare to include anti-retroviral therapy because it made them healthy enough to work and they also paid for the Security Fund as much as the others:

In fact I need it (Anti-retroviral drugs). I want all patients to receive the drug reimbursement because it's their right. We paid for social security welfare and fund at the highest rate like other workers. We also pay for the tax. So, we should receive the same right. O.K. This anti-viral drug is a little more expensive, but those who aren't government officials cannot get the same right... unfair... they said they can't draw back for that drug. The government should treat us with the same standard they used with the government officials....Why can't we have the right to anti-viral treatment? We should be treated as the others.

Fe5Phu, 432-436/ 14

The experts who provided treatment for persons with HIV/AIDS at a university hospital suggested that the treatment of AIDS should be covered in the social security welfare:

If low income patients pay for anti-retroviral drugs by themselves, they will not have the money to buy food. It is still unequal to provide anti-retroviral drugs for every HIV patient. We have the criteria of the treatment. The anti-

viral drugs should be provided when the patients have immunity lower than 250-200...Now the drugs are very much cheaper.... Firstly, the Social Security Welfare should cover the treatment of anti-retroviral drugs. We have to keep them to work for productivity.... When they get sick, we should pay for them. If we provided them with the short-term project and discontinue it, we should not provide the anti-retroviral drugs for them. It is useless...

D4R, In 6-12/6

Participant who worked as a volunteer and a leader of the HIV club raised the problem of the healthcare coverage that caused inequality right in access to anti-retroviral drugs. He expected the low price of drugs and equal right in the universal healthcare coverage. He suggested:

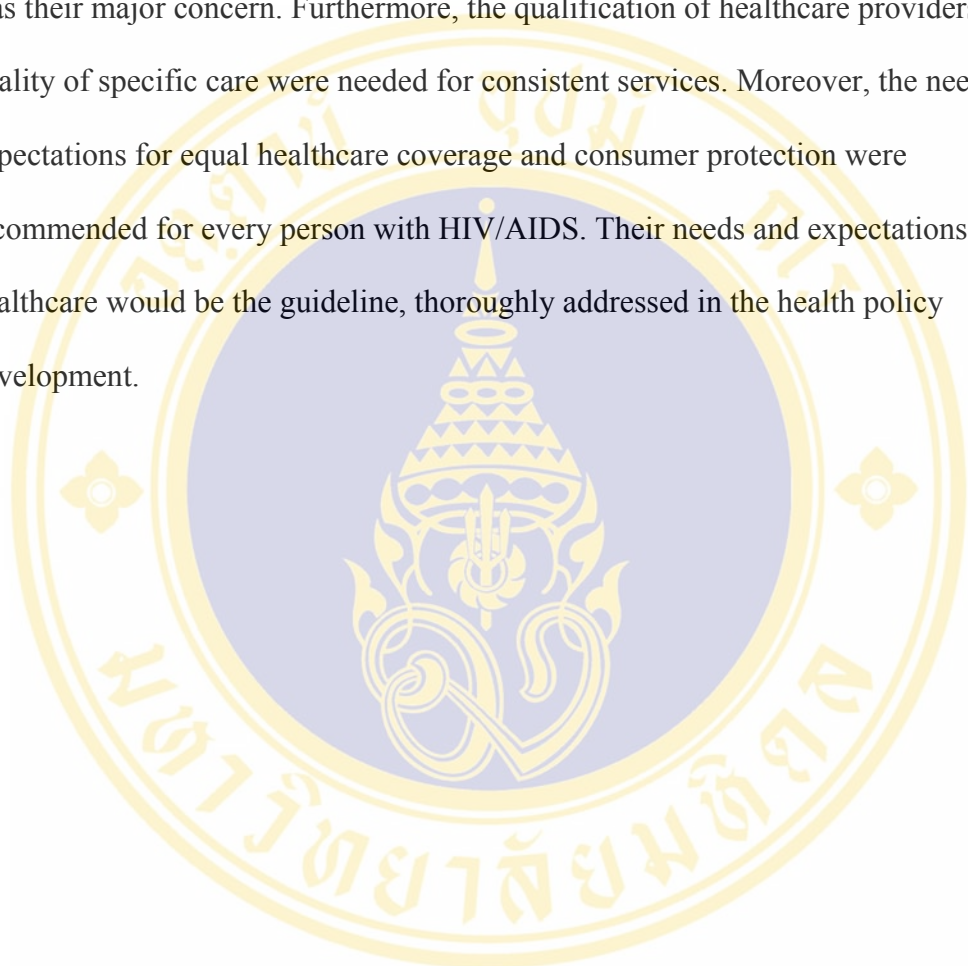
We hope that when the government produces the local HIV drugs and reduces the price of drugs, the drugs are cheap and included in the national drug list for us.....I hope for the equal right in access to the coverage of anti-viral drugs like other people because the right of healthcare should be equal. The people with AIDS are not the second class citizens. We should have equal right and the government should not discriminate against our right...

109-111/ 20, 125-127/ 21

Summary

This chapter reflects on participants who were successful in access to healthcare systems by accessing the health information system and using their own efforts to meet their needs and expectations. They could overcome sufferings by empowering themselves, leading to self-esteem and self-responsibility. They tried to seek various healthcare services to maintain and prolong their health such as being a member of an HIV/AIDS club that supported them to access specific programs of treatment and care such as the ant-retroviral therapy project, Day Care, home healthcare, and social support. Participants could gain benefits from the healthcare delivery such as ability to maintain self-development and ability to volunteer for healthcare development. Based on the experiences of persons with HIV/AIDS, they

raised their needs and expectation to improve the healthcare system in terms of equality and quality service provision with health promotion and illness prevention. They also requested for standardization and distribution of anti-retroviral therapy that was their major concern. Furthermore, the qualification of healthcare providers and quality of specific care were needed for consistent services. Moreover, the needs and expectations for equal healthcare coverage and consumer protection were recommended for every person with HIV/AIDS. Their needs and expectations in healthcare would be the guideline, thoroughly addressed in the health policy development.



CHAPTER VII

DISCUSSION

The content in chapter seven emphasizes the discussion of the findings of Chapter IV-Chapter VI that were categorized into the negative side and the positive side. The discussion of negative side includes experiences of HIV/AIDS sufferers in healthcare systems, health system constraints, as well as inadequate and unqualified healthcare providers. On the other hand, the positive side discusses existing effective healthcare services and sustainable effective care, followed by the issues to be considered in policy making for improving healthcare for persons with HIV/AIDS.

Experiences of HIV/AIDS sufferers in healthcare systems

This study advocates HIV/AIDS sufferers for equity healthcare. Though the sample of this study was a small group compared with the actual number of sufferers, qualitative research can reflect the picture of the underprivileged group's access to unequal healthcare and the unfair social support they endure (Harbermas, 1984: 216-222). The explanation of illness experience and the sufferings also reflects social and economic problems, which affect health status and utilization of healthcare of AIDS clients (Sakalys, 2000: 1470). In addition, it demonstrates that persons with HIV/AIDS are healthcare users who have extensive sufferings in disease experiences of their lifetime.

They also suffer from searching for quality health services and have difficulty in access to care.

Sufferers with AIDS disease experiences of their lifetime

The results showed that participants suffered from HIV/AIDS that affected their life such as family life, working life, and social life. The participants were AIDS populations who were young adults, and still had their productivity. More than half of the participants in this study were female widows whose husbands died because of AIDS. In addition, a few women still lived with their husbands who had a severe illness. Thus, female participants had to take care of the sick husbands and children and became family breadwinners even though they themselves were sick. Women with HIV/AIDS, thus, had to bear a double burden in looking after persons with HIV/AIDS both themselves and their family. This study was congruent with previous studies conducted with women in the developing countries who have traditional family roles as laborers (Bruyn, et al., 1995: 8).

A large number of female sufferers were in fact the household head who actually lacked adequate authority, money and tangible resources, family, and support to provide adequately for their children and themselves. Some of them returned to be commercial sex workers or mobile laborers in big cities. For this reason, they had risks of both secondary AIDS infection and AIDS transmission by their work. Moreover, AIDS-related community discrimination and extra care burden brought on by the disease worsened their condition, leading to an increase in these women's vulnerability. It demonstrated that the AIDS problems had not been solved with special disadvantaged groups who could not

access healthcare and support. Thus, to solve the social and economic problems for persons with HIV/AIDS, encouraging persons with HIV/AIDS to develop well-being by increasing their income with safety in work and supporting them to access health services should be taken into consideration. The preventive and care measure should be continuously encouraged and associated with healthcare services for specific groups like mobile laborers, women, children, and sex workers.

The results showed that most participants had completed only primary school and used to be laborers. It reflected that the undereducated persons with HIV/AIDS always have less opportunity to receive health information and the AIDS knowledge. Thus, they do not have an ability to protect themselves from AIDS transmission and prevent themselves from chronic diseases of opportunistic infection. They face with chronic illness resulting in their leaving their jobs and coming back to their hometown to receive family and social support. Most of them could not access the social welfare fund. As a result, they are in debts because they have to borrow money from family, relatives, and financial institutions. The results of the study were similar to those of the study of the economic impact of HIV/AIDS on households in rural Thailand which indicated that 300 HIV-affected households showed a 70.7% reduction in the total income resulting in poverty. As for strategies to manage the chronic AIDS mobility, they used various strategies which included reducing household consumption, reallocating labor, withdrawing children from school, and depending on family (Kongsin, S., et al, 2000: 6).

The results of the study also indicated that participants who had nuclear families who had no siblings/relatives and were poor could not take care of their non-AIDS infected children because of their disability. This means that if parents with HIV/AIDS cannot receive the quality and adequate treatment to prolong life, the number of orphans will increase. The poor relatives are also unable to take care of orphans because they already have to fend for themselves and their own family. It can also be predicted that the number of orphans will increase since their parents die before they grow up. As a consequence, Thai society will have the problem of AIDS orphans, which is similar to the pandemic of AIDS in Africa that makes orphans face educational and economic uncertainty, as well as a higher risk of malnutrition, chronic illness, and sexual abuse (Ademola, et al, 2000: 1-2). This situation clearly reflects the complicated and unsolved problems of AIDS in society that affect the well-being of individuals and family with HIV/AIDS. The awareness of the effect of AIDS on individuals and family should be raised for public health and social concern. The alleviation of AIDS problems and related issues should be mainstream in the encouragement of the persons with HIV/AIDS and family, enabling them to maintain their healthy life and well-being.

This AIDS situation affects not only households' income and individual and family's well-being but also national economic structures. The population income and national production will decrease because of the lack of working-age citizen. The results of this study are associated with those of the studies of the global AIDS epidemic that affects the enterprise level in developing countries such as South Africa. Persons with HIV/AIDS quit jobs or reallocate to work as laborers. Industries lose profits, and

investment and productivity decrease (International Labor Organization, 1999:13:UNDP, 2000:1-8). This study reflected the images of disadvantaged AIDS groups who have poverty, inadequate education, and dysfunctional working condition, leading to ill-health. Most of the AIDS sufferers are poor and have limited opportunity to access public and health welfare. Thus, health policy planners should make efforts to have disadvantaged AIDS group as their priority to increase their well-being, leading to social cohesion and good society.

Exacerbated suffering from utilizing healthcare systems

The results of this research further illustrated that HIV/AIDS sufferers made their efforts to seek healthcare and struggled in utilizing health services. Their stories of accessing the healthcare system delineated that sufferers tried to seek healthcare, both traditional and western treatment, to save their lives. This study indicated that sufferers were unsatisfied with ineffective and unscientific alternative treatment. The accessibility of AIDS treatment in health services was being denied to sufferers, especially life-saving medicine. Thus, they struggled with the healthcare services because they could not access or afford to pay for treatment like anti-retroviral medicines. This study was similar to others conducted in developing countries in Africa where the AIDS epidemic increase and is classified as the leading cause of death for all age groups, but most of them could not access anti-retroviral therapy and quality of care (Ifeyinwa, 2001: 1-8).

Furthermore, sufferers who were mobile laborers had difficulty with healthcare expenses because they had financial constraints and could not use their own health financial scheme to cover the cost of health services like local laborers. This study was

consistent with other studies (Johnson, 2001: 48; Salganicoff & Wyn, 1999; cited by Johnson, 2001: 48). They had hardship in accessing to care when they had illness because they did not have the coverage of anti-retroviral medicines and symptomatic treatment. These disadvantaged groups were also low-income workers who could not earn their living if they had health problems due to a chronic illness. Thus, the stories of mobile workers can be the evidence for making the measure to improve their access to healthcare. The health policy should be considered as producing the equal right as the other healthcare schemes for those who are immigrated laborers around the country.

According to the participants' stories, the healthcare they obtained was insufficient, and in harmful environment as they were pushed away from healthcare. Consequently, they had to waste their energy and expenses to seek for suitable quality healthcare. The women had no choice to select safety services such as being put to use illegal abortion services at private health sectors. It reflected that the government and healthcare services do not provide persons with HIV/AIDS with comprehensive information and avoidance of risky health services. The results of this study shed light on healthcare systems in that they had attempted to access healthcare to overcome their illness. However, they always confronted with unrecoverable chronic illness and agonies. The results often included mortal distress, as well as family and social rejection.

The results of the study also demonstrated that more than three-quarters of the participants had symptomatic AIDS with the opportunistic infection and were under threat from chronic diseases e.g. pulmonary tuberculosis (TB), pneumocystic carinii pneumonia (PCP), and cryptococcus meningitis infection which were the top three causes of death in

patients with HIV/AIDS (Division of Epidemiology, Ministry of Public Health, 2002: 1-3). Some people with HIV/AIDS had chronic illness due to low immunity level such as chronic diarrhea, oral candidiasis, wasting syndrome, skin's infection, and herpes zoster. On top of this, there were suffering from inadequate access to healthcare system because they could receive only symptomatic treatment. Owing to the late treatment and discontinuous drug compliance, some patients who had opportunistic infection such as TB still suffered from long period of treatment and its side effects. Some participants had health impairment from discontinued anti-retroviral therapy resulting in advancement of AIDS symptoms. It reflected that healthcare system for persons with HIV/AIDS lacks comprehensive effort to prevent the opportunistic infection and treatable diseases like TB. They could be the source of HIV/AIDS and TB carriers and transmission if the government overlooks to treat and control both AIDS and TB. This evidence also supports the situation of TB that it is the most common opportunistic infection that complicates persons with HIV/AIDS in developing countries and is responsible for about one-third of HIV-associated deaths worldwide (UNAIDS, 2000 a:31). It implies that the health policy does not have a proactive and strategic plan to promote health for people with HIV/AIDS by emphasizing the improvement of their immunity and establishing the strategies to promote treatment adherence. As a result, most of the sufferers in this study did not overcome suffering from utilizing appropriate healthcare system.

The healthcare system constraints

This study advocates HIV/AIDS sufferers for equity healthcare. Sufferers had difficulty in healthcare access due to healthcare system constraints. Their perspectives of healthcare were not matched with policy makers' plans because the systems did not serve their healthcare needs. They also demanded and interacted with healthcare system in equivalent proportions. Thus, they should have acute images of the health system that is valid for all. Issues, particularly insufficient distribution of healthcare provision issues, quality and standard of AIDS treatment, health financing in HIV/AIDS care, and understanding of health policy makers are still abound. The illustration of their perspectives toward healthcare system constraints are discussed as follows:

Distribution of quality health service provision

The results of this study indicated that several sufferers could not access adequate and continuity healthcare services when they had firstly been informed they had HIV infection until they had developed AIDS symptoms. The participants' perspectives were in agreement with the national AIDS policy in the issues of mobilizing the use of resources. However, most of them were unsatisfied with insufficient and ineffective strategic plan implementations. It implied that the healthcare system for persons with HIV/AIDS does not run for every person with HIV/AIDS equally and effectively. The difficulties of healthcare access and the unavailable distribution of service provision were related to the centralization of service provision and the geographical environment. The participants who lived in rural areas had difficulty in utilizing specific healthcare services because they were exhausted from spending more money and wasting a long time for

transportation. Sufferers needed more healthcare when they had a chronic illness. However, the provision of treatment and care at community healthcare centers near their residences did not respond to their health problems and needs. They were confronted with inadequacy and too many patients at central healthcare settings. The results of this study were congruent with the study of the problems and suffering of Thai people when utilizing public healthcare services (Sawangdee, Y. et al, 2000: 62). The evident situation reflected the services in healthcare that were not comprehensive and there were no effective referral systems. Furthermore, the implementation and resource allocations of each health problem related to HIV/AIDS such as drug addiction and reproductive healthcare was separated, and there was ineffective cooperation among each healthcare service. The system lacked tangible strategic plan and evaluation to promote adequately continuity of care in community healthcare settings located near their houses. Thus, the integrated health services like one-stop shopping services that offer multiple services at the same location should be considered for persons with HIV/AIDS.

The findings of this study were in congruence with the study of Medecins Sans Frontieres in an AIDS program in Thailand (Wilson, 1998: 1-2) in that healthcare for persons with HIV/AIDS was centralized, involved high cost, and was mainly provided by large specialist hospitals in central and big cities. The findings also indicated that the community based care and home care services were limited and not available in all healthcare settings, because strategic plans still lacked proactive services in distributing the resources allocation to community health settings. The main focuses of service provisions were still hospital-based services without a referring system from the tertiary

care to their community hospital. Although there was a policy that encouraged family and volunteers to participate in taking care of their HIV/AIDS family members, sufferers and caregivers were confronted with care burden because the system lacked effective and continuous community cares like collaboration of home visit by health professionals. The primary and community healthcare was not constantly established nor decentralized to comply with the client-centered approach and involvement of family and communities. The referral networks between different levels on healthcare systems and social welfare did not function either. The strategy to improve continuous and quality of care should increase community resource allocation and initiate proactive care linking between tertiary care and community services. Thus, capacity building and collaboration of home and community care should be considered as an important matter to improve quality and adequate care for patients with AIDS at home.

Quality and standard of AIDS treatment and care

The study also illustrated that sufferers were unsatisfied with anti-retroviral therapy offered by public healthcare and had inequality in accessing quality treatment of anti-retroviral medicines. It reflected the quality and standard of AIDS treatment for HIV/AIDS which had limitation of access for some patients. Their perspectives were against the issue of cases selected for anti-retroviral treatment and short-term AIDS projects for mothers with HIV/AIDS. Sufferers perceived the quality of treatment as a double standard because only few participants received the AIDS treatment for free, while others received only symptomatic treatment. The limited projects raised ethical issues of who should be included or excluded in the governmental anti-retroviral projects. This

finding was similar to the projects in developing countries like Zambia which showed that persons with HIV/AIDS who benefited from antiretroviral projects felt guilty because their friends were not lucky to be included in the project (Zulu, 2001; cited by von Schoen Angerer, et al., 2001: S81-S90).

Furthermore, the evidence of limited access to quality treatment and care was consistent with the study of the impact of economic crisis on the AIDS prevention and control program (Pothisiri, P. et al, 1998: 114-15). The study also reflected limited resources in provincial hospitals resulting in limited access to anti-retrovirals and drugs for opportunistic infection because these special drugs were given in the healthcare settings where a comprehensive approach to treatment was assured. The outcome of the treatment project was poor due to ineffective regimens of dual therapy and discontinuous anti-retroviral project. The encouragement of patient compliance and physician adherence to protocols still lacked correct information and effective health teamwork across the continuity of care (Kunanusont C., 1997: 109-113). Thus, sufferers had drug resistance and health impairment due to discontinuous AIDS project offered for only one year and other ineffective care. This shed light on the failure in the management of short-term AIDS projects that were not cost-effective interventions. Thus, strategic plans should be reconsidered for national anti-retroviral drug lists to improve the equal and prolonged access for persons with HIV/AIDS. In addition, quality treatment and anti-retroviral treatments should be the priority for research and development including providing drug information and monitoring to promote drug adherence.

Healthcare financing of HIV/AIDS care VS Healthcare coverage

The results of this study indicated that the sufficient budgets from the central government were important resources for implementation of the policy. For instance, health services such as day care and counseling services were the main service provisions that encouraged persons with HIV/AIDS to have psychosocial support and access to healthcare systems. However, some healthcare settings in other provinces could not maintain these services due to the problems of unsustainable budgets to run the projects. For instance, the day care project managed by community hospital could promote participants to join the activities and receive tangible support like reimbursement for transportation. According to the inadequate and discontinuous support from governmental budgets, the project could not be run leading to a reduction in the number of patients with HIV/AIDS who received appropriate services. This situation was in accordance with the study of funding priorities for the HIV/AIDS crisis in Thailand (Pothisiri, P. et al, 1998: 13) which illustrated that limitation of budgets led to interruption of program operations. The cuts in the program budget had impacts on the projects of empowerment of individuals and communities as well as coordination with non-governmental organizations and non-medical interventions.

This study also indicated profound access difficulties for participants who had a variety of health financing schemes and could not use health welfare as equally as those who had different chronic illnesses. Sufferers who had social security scheme or the civil servant medical benefit scheme were suffering from high cost of healthcare expenses that were not covered in the national drug lists. Although the present government has launched

universal healthcare coverage for those who do not have previous insurance, the government has adjusted the health-financing system in terms of hospital's subsidization, at US\$ 27.9 per person per year, according to number of registered population in service area. However, the benefit from the scheme also does not cover anti-retroviral drugs for persons with HIV/AIDS (Tanchareonsathien, V., et al., 2001: 381-390).

It is estimated that if a scheme were to cover all people with HIV/AIDS, it would require US\$ 144.93 million to obtain anti-retroviral drugs for all persons with HIV/AIDS in 2002. In addition, it would be equal to 9.5% of health spending or 0.7% of the total government spending (Teokul, W. 2002: 5). However, the actual public expenditure per capita was US\$ 232. The highest actual expenditure per capita was for education because the constitution has mandated basic education up to twelve years. Thus, the government will be required the essential resources to complete this objective (Teokul, W. 2002: 5). The anti-retroviral drugs are not considered for free treatment in all healthcare schemes because the drugs are not added into the essential national drug list, and the AIDS treatments are adjusted as being under investigation (Office of Health Care Reform, 2001: 30).

The study showed the situation that poor sufferers could not afford even the low cost of anti-retroviral drugs produced by the government. Although the Thai government intends to support persons with HIV/AIDS by manufacturing low cost anti-retroviral drugs, costing about 1,200 Baht or US\$ 27 per month (Agence France-Press, 2002:1), the cost of anti-retroviral drugs is high when compared with their monthly household income that is less than 2,000 Baht. This is an unfair health financing policy that lacks financial

protection against the cost of health and illness for the disadvantaged group. The poor AIDS patients have to spend a large share and out-of-pocket money than the rich ones (WHO, 2000a: 8, 30). This evidence indicates that the current and future economic constraints make the government face with difficulties in mobilizing additional resources to provide the demand for anti-retroviral drugs while poor sufferers face with chronic illness and disability as they are struggling for anti-retroviral drugs access. This matter should facilitate the government to reconsider the universal healthcare coverage and ensure equality access for people with HIV/AIDS.

Policy makers' understanding of HIV/AIDS

The sufferers' perspective of policy makers could reflect the inequality of access to healthcare system, especially the equal right of universal healthcare coverage of anti-retroviral drugs. The findings could illustrate participants' viewpoints that were against healthcare policy makers in a few issues. The healthcare coverage policy was an important issue that most participants were against because the government provided the healthcare coverage for patients with all chronic illnesses except for the treatment of HIV/AIDS. For the public healthcare scheme, the anti-retroviral drugs are covered to prevent the mother-to-child transmission because it is considered cost-effective, whereas anti-retroviral treatment of postpartum mothers is not. In addition, anti-retroviral medicines are considered as drugs under investigation. Therefore, they are excluded from the essential national drug list for healthcare coverage and social security welfare (Office of Health Care Reform, 2001: 30, The Social Security Office, 1999: 228-229).

However, the participants learnt about updated treatments of effective anti-retroviral therapy and equal right to healthcare coverage in developed countries (The White House, 2000a: 1-4; Agence France-Press, 2002: 1). They perceived that HIV/AIDS was a chronic disease like other diseases, whereas the government perceived it as misbehavior disease. Sufferers and families may feel that their right and expectation were disregarded when quality treatment was restrained due to these controversies. On the other hand, healthcare providers especially physicians could not provide the best possible available treatment because of the disagreement between the public health considerations about equitable access and cost effectiveness, and sufferers were concerned with life-saving treatment available, but they could not have the right to access.

The results could also reflect the Thai health policy that is dominated by policy makers who might have prejudice against HIV/AIDS because they treat other behavior-induced diseases such as heart disease, cancer, and diabetes mellitus differently. The policy makers in developing countries may feel that an adequate prevention program is key to decrease the growth of HIV infections. Thailand is one of developing countries that spend budgets on AIDS prevention and care but does not cover the anti-retroviral therapy. In 2001, the government spent on the HIV program about 0.16% or \$US 0.54 per capita (The Office of National Economic and Social Development Board; cited by Teokul, W. 2002: 4). This reflects that the budgets that the government has spent on total public expenditures are overall modest in Thailand. However, the lesson learned in African countries is that they addressed only prevention strategy without strategic plans for care

and treatment. Therefore, they are now facing uncontrollable HIV epidemic (Act up-Paris, 1998: 2).

The most important matter that affects the country is the commitments of the policy makers to delete or amend an enactment that reduces the incidence of AIDS and expands access to HIV/AIDS care. The healthcare policies that extend access to care are significant level interventions with implication for both primary and secondary HIV prevention. Providing quality of care and medications to prevent opportunistic infection of HIV-infected people is a potentially important HIV prevention method in terms of secondary prevention. In addition, providing highly active anti-retroviral therapy that reduces the viral load may also decrease infection of individuals. Thus, policy initiative is essential to expand healthcare coverage for both primary and secondary prevention (Shriver, et al., 2000: S57-S62).

As for lessons learned in developed countries such as in the U.S.A., the introduction of triple combination anti-retroviral therapy in 1996 led to a decrease of 70% in deaths caused by AIDS (WHO Press release, 2002: 2). In Brazil, the policy makers have shown the political commitment and viewed civil society as an ally. The Brazilian government distributes free anti-retroviral drugs and many of the low cost drugs are manufactured in Brazil. The effectiveness of access to anti-retroviral therapy in Brazil is evidenced by AIDS deaths, which have declined by 73% (UNAIDS, 2000a: 101-102; WHO Press Release, 2002: 2). The encouragement of anti-retroviral therapy in some developing countries may challenge policy makers to reconsider the anti-retroviral therapy as comprehensive coverage in the HIV/AIDS care policy.

Recently, The Thai government has co-operated with the Thai government Pharmaceutical Organization (GPO) to manufacture quality, low-cost generic drugs and has made a significant financial commitment to scale-up generic production with universal coverage for persons with HIV/AIDS. However, GPO production operates on a small scale, supplying individual hospitals and NGOs projects. The activists reflect the slow responses of policy makers and limitation of achievements (von Schoen, 2001: 85-90). The voices of sufferers can initiate policy makers to better understand HIV/AIDS as controllable chronic disease and to balance investing resources for anti-retroviral therapy and other complicated treatment of AIDS with the increasing demands for treatment of other chronic diseases like cancer and cardiovascular disease.

Understanding of family and community on HIV/AIDS

The findings in this study indicated the hindrances of access to care are high social costs and expense out of the healthcare system. The patients with HIV/AIDS were their family's burden because they were disabled from chronic illness. They could not earn money for their living. As a result, they lacked social cost to maintain their daily living and acquire basic necessity and transportation to hospitals that further impeded their accessing continuous care. According to their stories, persons with HIV/AIDS have double burdens of themselves and their caregiver's role. Widows with HIV/AIDS had difficulties in accessing community resources and were burdened with their children. Low-income with aging caregivers had to take responsibility of their young HIV/AIDS children. Therefore, some of AIDS patients were left without continuous care in their houses. These stories reflected the limited resource in community and social

discriminations against AIDS which are still imprinted in Thai societies. This situation of social discrimination in some parts of Thailand such as the center and the south force sufferers to seek healthcare and social support outside their community because having to disclose themselves can have impacts on their family and occupation.

Although the Thai government has campaigned and promoted the social acceptance of people with HIV/AIDS, the impacts of community discrimination could still be seen. For example, children of HIV-positive parents often denied the right to go to school and have unequal access to community resources. This evidence is consistent with that in other countries where people in community lack understanding of AIDS (UNAIDS, 2002: 11). In this study, the community discrimination may stem from the limited implementation of prevention and education program that focused on small target groups primarily in Bangkok and the northern region. The national campaign did not reach more population in rural areas around the country (Lyttleton, 1996:25). According to the former National AIDS Plan, the most budgets used to support the HIV/AIDS program were catered in the north while sufferers in other regions lacked appropriate supports (National AIDS committee, 1998: 26-32). The results also reflects that the National AIDS Plan still lacked a continuing HIV/AIDS campaign to increase AIDS understanding in community. Thus, strategic plans and resource allocation are needed to empower local people in community with knowledge and skill to reduce negative attitudes towards AIDS and enable them to support AIDS persons in their community.

Inadequate and unqualified healthcare providers

The results illustrated that participants were unsatisfied with healthcare providers' prejudice and discrimination. It implied that healthcare system still lacks plans of continuing human development to advocate and respect dignity of the sick persons and responding to their health needs (WHO, 2000 a: 31-32). The prejudice healthcare providers may result from power and domination throughout society like the hierarchy of the Thai social class. Persons with HIV/AIDS experienced self-stigmatization or the shame when they internalized the negative responses and reactions of others (UNAIDS, 2002: 9-10). Besides, the poor persons with HIV/AIDS felt worthless and devalued by healthcare providers who were domination. Thus, they felt themselves were opposed by healthcare providers.

In addition, healthcare providers' negative attitudes against HIV/AIDS produced the interruption of health provider-client relationship affecting quality of care. In so doing, healthcare providers violated their right and denied health services to them (UNAIDS, 2002: 10). This study also indicated that healthcare providers were not prepared for HIV/AIDS education and trained for HIV/AIDS care so that they perceived AIDS as a severe incurable disease. They had to confront with the work load of AIDS patients, had fear of infection, and had no willingness to treat and care. This result was in accordance with the situation of AIDS pandemic in the U.S.A. because of ineffective treatment and unprepared healthcare providers in the mid-1990s (Sherman & Quellette, 1999: 35-43). Moreover, in developing countries such as India, people with HIV/AIDS were discriminated against in private hospitals in terms of denying treatment outright or

imposing mandatory HIV testing prior to surgery or child delivery. The constraint of healthcare systems in terms of inadequate equipment such as gloves, masks, and post exposure prophylaxis could cause further healthcare providers to deny care and have fear of occupational exposure (Khan, 2000: 16). Thus, the consistent healthcare system needs to emphasize the updated education and technical support to improve healthcare providers' capacity and reduce negative attitudes towards HIV/AIDS.

The results analyzed from participants' stories and fieldnote records could be indication of the existing healthcare systems in terms of unqualified and inadequate health staff. The sufferers had difficulty in access to quality of care because health staff in community healthcare could not provide updated AIDS information about AIDS disease and treatment. In addition, the specific treatment of HIV/AIDS was not available at community hospitals. Thus, several sufferers tried to seek anti-retroviral treatment at provincial hospitals. This pointed out that the human resources like nurses who were gatekeepers at community based care lacked adequate knowledge about HIV/AIDS, especially disease prevention, treatment, and health promotion. This evidence was in accordance with other studies in Thailand (Boontong, T., Ed, 1999: 66; Senarat, V. 1999: 312). Most nurses who worked at a primary level were only technical nurses or public health workers who did not have a university degree education. They were not able to perform treatment on complicated symptoms as appeared in HIV/AIDS patients. Most of the treatments offered were medicine to relieve the symptoms such as painkiller. Distribution of support at the community level was also limited because most of the personnel had lower than a bachelor's degree, and lacked medical practice in primary

treatment and referral care. Thus, healthcare providers need educational support to improve special skills in community care.

However, in some provincial hospitals, few health staff had updated specific knowledge of AIDS and standard treatments especially anti-retroviral therapy. However, some general physicians could not offer adequate AIDS information and self-monitoring including prophylaxis therapy to patients with HIV/AIDS who needed more information of AIDS treatment. Although participants could access anti-retroviral therapy projects, they received inadequate information about the efficacy of treatment, support, and monitoring. Thus, the participants were faced with poor adherence and increased drug resistance. This study is consistent with other studies of drug adherence (Sirgel & Gorey, 1997:15-22; Richter et al., 2002: 25-32). The results reflected the quality of healthcare infrastructure that was not appropriate for anti-retroviral therapy. Healthcare providers should give sufficient information, provide adequate support and motivate patients for good adherence. The effectiveness of anti-retrovirals implementation should develop healthcare providers' capacity and simplified treatment protocols and effective monitoring should be for use as standard as in western countries (Medecines san Frontiers, 2001; cited by von Schoen, et al., 2001: S81-S90).

Existing effective healthcare services

According to research results, there were a few participants who had positive experiences and were still healthy enough to contribute to group membership and society. Such verified data showed that there were a few participants of HIV/AIDS who could

access special health services provided for persons with HIV/AIDS. The existing effective healthcare services were described in terms of effective services with limited healthcare access, an example of successful program and activity, as well as participation in sustainable access of effective healthcare.

Effective services with limited healthcare access

The findings in this study showed the effective healthcare services that were limited for several persons with HIV/AIDS. The participants who had positive experiences in health services could gain a sense of empowerment and hope for living. Some participants who had symptomatic AIDS and had a good opportunity in access to anti-retroviral therapy projects expressed that they were lucky and satisfied with care and treatment they received. The effectiveness of anti-retroviral therapy also brought about positive attitudes and adherence of drugs in pregnant women. Their compliance was contingent on being assured of the effectiveness of treatment and care. For example, female participants who had taken anti-retroviral therapy have achievement in the birth of a non-infected baby. The special clinic of HIV/AIDS promoted participants to access medication, and treatment information, quality prophylaxis therapy, immune monitoring, and illness prevention. The results were consistent with those of other studies which found that people living with HIV/AIDS were more encouraged to comply with treatment regimen if they believed in the efficacy of treatment (Misener & Sowell, 1998: 431-447; Aversa & Kimberlin, 1996: 207-219). Thus, this study showed the good outcome of anti-retroviral therapy to reduce mother-to-child transmission; however, the prolonged treatment for life-saving of the mothers is limited.

The positive experiences of persons with HIV/AIDS who could access to the long-term anti-retroviral project sponsored by NGOs were good evidence base of cost-effective treatment. They could have health improvement, recover from opportunistic infection, and return to earn money for family. Some of them were able to be contributors and work as volunteers in healthcare settings. This result was one example that was consistent with other studies in high-income countries that many people who are alive with HIV could work productively because they receive highly active anti-retroviral therapy (WHO Press Release, 2002: 2).

The stories of positive experiences in accessing quality of treatment and care with specialists are examples of inequality distribution of healthcare services that are specific for persons with HIV/AIDS. However, more persons with HIV/AIDS were suffering, while only very few of them could reach the specific treatment and care.

An example of successful program and activities

Although some persons with asymptomatic HIV infection do not take anti-retroviral medicines in the early stage of disease, they have abilities to maintain self-management and self-monitoring that prevent illness and delay AIDS progression. The individuals' capabilities and access to information enhance people living with HIV/AIDS to have motivation to engage in self-care practice and treatment adherence. However, when they have lower immunity, they need anti-retroviral therapy to prevent AIDS symptoms. The inequality in utilizing anti-retroviral therapy across HIV/AIDS groups have an impact on access to equal treatment and human right. All persons with

HIV/AIDS would like to have their right to maintain their good health and receive the good quality of care and treatment from healthcare services (Criminal Court, 1998: 18).

In the present study, the AIDS program activities such as the empowerment of individuals created successful healthcare access for participants who made human efforts against their illness. Although the most specific healthcare provision was settled at health institutions, participants could gain positive benefits and satisfaction. This is an example of healthcare system to promote the persons with HIV/AIDS who firstly access healthcare. Their abilities should be empowered to allow them to gain sustainable self-esteem and mutual collaboration in healthcare systems. Their self-contributors and consumer groups in raising the government's awareness of AIDS problems are similar to the movement of HIV/AIDS networks and NGOs in Thailand (HIV/AIDS Networks and NGOs, Thailand, 2001). They act as key players with the national health policy and advocate healthcare equity. They request for equal treatment of anti-retroviral medication coverage under universal healthcare plans. One example of the success is the strong movement of activists which forced the government in Brazil to provide every person with HIV/AIDS free HIV/AIDS treatment (UNAIDS, 2002: 17). Thus, health policy in Thailand requires voices of HIV/AIDS clients to be accounted for and justified for equal healthcare access.

Participation in sustainable access of effective healthcare

The positive and negative experiences of participants offered a penetrating criticism of Thailand healthcare structures. The narrative relation is a mutual interaction in the form of inter-subjectivity and shifts participants' view of themselves from being

overpowered to having a sense of empowerment. While telling stories of experience in healthcare, persons with HIV/AIDS can gain insights through critical self-awareness by reflecting on their experiences with the investigator. They could undertake the concrete actions for the improvement of healthcare in terms of healthcare needs and expectations (Stevens & Hall, 1992: 4).

To establish health policy appropriate for persons with HIV/AIDS, healthcare needs and expectation are required for shifting in the traditional balance of power in the interaction between the consumers and the health providers and the healthcare system. Healthcare needs and expectation of persons with HIV/AIDS from this study indicates in terms of consumer or patient-centered care. The results from the narratives of healthcare indicated that participants or consumers were qualified to determine their own needs and expectations. They were able and had the passion to make decisions and preferences about what they needed and wanted in the healthcare system (Lutz & Bowers, 2000: 173-174).

The infrastructures of healthcare system and socioeconomic hindrances to access that participants expressed indicating distress, hopelessness, discrimination and struggle in seeking treatment and care including lack of self-determination and discontinuation of care. The negative and suffering experiences foretold the threat of healthcare that inhibited health promotion and illness prevention, the key elements of healthcare reform. However, those were participants who had positive experiences and satisfaction with the outcome of care and treatment that met their needs and expectations. The sustainable participation in access to effective healthcare are as follows:

Healthcare coverage for primary prevention and treatment

Every participant reported their needs of service provision in terms of equity, quality, and adequate health services that promote health and prevent disease progression of AIDS. Their requirements of early detection and health promotion are the basic rights of their health. Thus, counseling to promote health and immune monitoring are necessary for all persons with HIV/AIDS. The need and expectation for quality anti-retroviral therapy to prevent illness and to improve their immunities are necessity for healthcare. It is implied that participants had an awareness of and responsibilities for their health to maintain their function for themselves and family. They wanted to actively participate in decision and alternatives concerning their health problems. The voices for needs and expectation for healthcare are clients' rights in good health that will transform the traditional model of healthcare delivery to be consistent with balanced relationship and partnership between providers and clients.

Respect for dignity, autonomy, and confidentiality

As HIV/AIDS is a sensitive issue in society, participants needed health providers to keep their confidentiality when they utilized health services. They required safe and virtuous healthcare surroundings in which they could gain a quality of healthcare delivered with respect and dignity by consistent and qualified health providers. Components of quality that each participant identified as important included specialty cares in specific units. They needed to feel safe when they performed the caregiver role in hospitals and their environments. Their needs and expectations of healthcare for dignity, confidentiality, and autonomy to participants in choice are basic elements of

responsiveness in respect for persons with HIV/AIDS (World Health Organization, WHO, 2000a: 32). These elements show the scope for improving health system performance in these respects. Promoting clients as collaborators in healthcare decisions and choices can be cost-effective. As a result, client consequences and compliance to medical treatments and care can be enhanced. The needs and expectations of care are consistent with those shown in other studies (Chewning & Sleath, 1996: 389-398; Stewart, 1995: 1423-1433).

Client orientation and comprehensive healthcare

Participants' needs and expectation of prompt attention, amenity of adequate quality, access to social support, and freedom to select cares are the basic client orientation. The elements of client orientation demonstrated how health systems were highly unresponsive in this study (World Health Organization, WHO, 2000a: 31). The suggestion and requirement for amenities of adequate quality, such as infection control to prevent opportunistic infection, safe abortion services, and hospital nutrition, are basic needs of qualified health services. The needs for sustainable social support networks for persons with HIV/AIDS including family and their children can promote ease and facilitate access to healthcare. Furthermore, prompt attentions such as actively responding to, supporting patients' emotion, and arranging reasonable waiting times for out patient-services are still major problems of access to quality care.

Participants in this study who lived in remote areas needed to select quality health services near their residences in order to save their social cost. Thus, quality and comprehensive primary healthcare is their requirement. On the other hand, participants who lived in cities needed to select health services that could keep their confidentiality.

Appropriate healthcare services are considered based upon clients' culture and geographical areas. Therefore, acknowledging responsiveness in terms of client orientation is an essential aim of healthcare systems. These aspects can involve an assessment and establishment of health systems that serve clients' satisfaction and meet their needs.

Issues to be considered in policy making to improve healthcare for persons with HIV/AIDS

The story of experiences in accessing healthcare of the sampled groups in different provinces in Thailand could definitely describe the overlapped and unfair health service provisions, especially the civilization and complete healthcare services provided only in the capital or big cities. The findings of this study reflected the bureaucratic complexities, out of pocket costs, social costs, and restriction of healthcare structures which obstructed access. Most of the participants with HIV/AIDS who did not have health welfare, were poor, were mobile laborers, or had no income still suffered. They had to pay high cost compared with their income. Their sufferings were not different from the sufferings of those who lived in remote provinces where there was no special clinic for AIDS treatment or lacked quality of care and experts. These clients' experiences and their needs could lead to the better understanding and could be the evidence base to develop the strategic plan for implementation.

The issues to be considered in policy making is developing and focusing on what sufferers perceived as important and necessary to meet their needs in healthcare systems

and how to incorporate these preferences into service delivery (NINR, 1999: 3). Moreover, the healthcare services should be developed in collaboration with healthcare team such as nurses, physicians, therapists, and other healthcare providers with the consumers as a partner at the center (Meleis, 1991: 114). Thus, the addressed issue for the model of healthcare needs for persons with HIV/AIDS should be developed with justice, quality, and sufficiency as follows:

Equality distribution of anti-retroviral therapy

There was a difference in treatment quality between persons with HIV/AIDS who did not join the anti-retroviral therapy project and those who joined the project. The results showed that participants who had received the quality treatment without side-effect sufferings became better and had better well-being. They had gained the better treatment and care compared with those who were not project members. As a result, the criteria about anti-retroviral therapy should be considered carefully in order to distribute the cost-effective service and care to most, if not all. The requirement to overcome these barriers are sustainable funding for continuing supplements of anti-retroviral drugs, adequate healthcare infrastructure, and simplified treatment protocols (Brundtland, 2001: 5). Thus, research and development is needed to simplify treatment protocol leading to low cost with low technology testing methodology.

Health personnel development

The personnel development through the skill training of health promotion, early detection, immune and viral load monitoring for physicians and care providers in health stations or healthcare centers, community hospitals, and provincial hospitals can

help persons with asymptomatic HIV access health services more easily. They would be able to take care of themselves and have more knowledge in practicing self-care.

Furthermore, assembling AIDS experts who have therapeutic communication skills to be counselors should standardize counseling services of both governmental settings and private sectors. Those consultants should help AIDS infected patients understand how to deal with stress and sadness. Mental adjustment aid, stress control aid, life planning, monitoring, and adequate comprehensive care can give the sufficient data of self-preservation and effect of the continuous treatment. Furthermore, there should be an encouragement to urge persons with HIV to join HIV/AIDS patients' club in order to receive help from community network (Stevens & Doerr, 1977: 535-536). Telephone counseling service should also be provided for people living with HIV/AIDS and family who feel anxious and need advice in order to get rid of stress and increase their self-esteem. They would live happily and have the longer working ability without taking anti-retroviral medicines, so the necessity of drug in the asymptomatic groups would be decreased when they have normal immunity level.

Quality, decentralization, and continuity of care

It is very important to standardize treatment and care and the develop healthcare staff efficiency in the nearby community hospitals since it can decrease the work load of the central hospital. There should be a treatment referral network to look after the asymptomatic patients to help them live without complication diseases and to treat the symptomatic patients to recover from opportunistic infection. A standard anti-retroviral therapy research and development should be provided to community hospitals by

developing network from provincial hospitals and providing experts or special physicians as the mentors who teach knowledge of standardized treatment. Moreover, there should be a monitoring program and a consideration that covers the necessity of drug treatment in the following groups: mothers who give child-care, breadwinners, and pregnant women, as well as and the methods to enhance adherence. As a result, cheap-and-effective innovation development such as the total lymphocyte count to replace CD4+ cell count test should be provided to infected persons in the nearby health service centers in order to monitor clients' immunity level and early-stage treatment. The essential matters of treatment are the primary prophylaxis and the early diagnosis. The treatment of opportunistic infection should be considered in HIV/AIDS patients with CD4+ cell counts less than 200 cells/ μ l (Sanne, 2000: 6-7; Ruxrungthum, K, & Phanuphak, P: S1).

Effective primary healthcare and specialists

The one-stop shopping service is offered at special clinics e.g. special HIV/AIDS treatment clinic and drug addiction clinic. The emotional and mental support consultant service in community hospitals is one of the health services to which persons with HIV/AIDS can conveniently access. This integrated treatment should be considered to provide at community-based care because it costs less than hospital-based care. According to care service characteristics research, people with HIV/AIDS who received treatment from community-based care settings could recover more quickly and were able to resume their daily work (Gill, et al., 1998: 4). Furthermore, the one-stop shopping service should be provided by a family health service e.g. women' health and reproductive health service for unwanted pregnancy advice and alternative problem-solving including the family

planning service which can prevent the secondary infection and offers enough condom supplement.

In addition, to encourage persons with HIV/AIDS to gain access to treatment continuously, the government should build the effective service networks. For example, treatment and care can be referred from central hospital with hospital accreditation for the continuous care of opportunistic illnesses to community care. The special wards for HIV/AIDS patients at hospitals in some areas can enhance the effectiveness of caregivers and volunteers in providing care. The effective referral system, which is a primary healthcare, should be distributed from hospitals to nearby health service settings.

Development of skills and quality of health staff such as nurse practitioners or family nurses is important as they are key persons in resource-poor settings. They can play vital roles in disease monitoring and administering continuous medication such as opportunistic infection drug refill, home care, rehabilitation care, and end-stage care. Thus, patients would receive the continuous quality of care. In the country that is successful in providing family and community care for patients with HIV/AIDS, the nurse practitioners are the important staff who can access people's needs and help them solve their health problems. The nurse practitioners provide care and treatment to HIV/AIDS patients who live in rural areas. They can make decision on treatment, perform treatment with consultation from experts, and provide consultation to patients and their family (Lewis & Miramonte, 1999: 39-42). Moreover, the nurse practitioners are both client advocates and case managers. They provide care and treatment so that the patients' physical and mental needs are met (Kirton, et al., 1999: 72). Thus, with the lack of public

health staff such as in Thailand, the nurse practitioners are the important staff of HIV/AIDS clients in community health services and primary healthcare settings.

Quality networks and referral care

The results from the participants' stories indicated the lack of coordinated health and support services. Therefore, an integrated case management system is suggested to be an example of service based standard of care in community healthcare settings (Sowell & Meadows, 1994: 53-64; Sowell & Grier, 1995: 15-21). The use of an interdisciplinary case management team such as nurse experts, social workers, counselors, and therapists to develop client-centered plans allows clients to benefit from a broad range and continuum of services. Clients with all levels of needs and health problems can access the case management services. For instance, with early phase and low needs, intense planning is to empower clients by providing the guidance on how to manage their lives. In addition, ongoing information and mental support can promote clients to cope with the threat of AIDS. Clients who are in the high-need phase or with acute needs are extremely vulnerable with the increasing financial problems, instability, and health deterioration. Case management system is to develop a comprehensive, long-term care that support clients to gain an effortless transition from independence to a more-supported status. The clients can receive intensive monitoring and relevant and practical services including early intervention clinic. Therefore, to develop comprehensive and continuum of health service in community-based care, the model of case management is considered.

Family and community participation for home care

To encourage family and community to take account for persons with HIV/AIDS in society is the main policy of Health Care Reform (Nitayarumphong eds, 1997: 157). Community understandings and the adapted government policy in the AIDS campaign would help persons with HIV/AIDS and people in community be able to live together. Furthermore, the adequate budgets are required to encourage NGOs and community to take part in the care provided to end-stage patients who are homeless and have no social support. This aid would help people living with HIV/AIDS receive the palliative care until the end of their life.

To develop caregivers' skill and support in nursing aid supplies by health settings, social resources and network of patients' relatives would decrease their burden in caregivers' role at home. As a result, home care services should be provided in comprehensive services with the integration of multidisciplinary team such as nurses, social workers, and volunteers. This model of integration can reduce the cost of care and provide more holistic care than conventional home care (Cherin, et al., 1998a: 55-72; 1998b: 55-72).

According to the study of patients with HIV/AIDS's experience in home and community care, there was less home healthcare provided for patients with HIV/AIDS. They were not suitable services appropriate to the increasing number of persons with HIV/AIDS. As almost all persons with HIV/AIDS need continuity and quality of care when they have progression of the disease, proactive healthcare services should be

provided in order to prevent illness and offer rehabilitative health services at primary healthcare settings such as home care and community-based care.

Adequate budget and human resources for specific care

Specialized treatment and healthcare staff are the important factors to encourage people with HIV/AIDS access to health service. According to the observation of health staff's working and environment conditions, specialized treatment staff such as physicians and staffs of Day Care clinic must have positive attitude and comprehension in treatment and to be able to offer health consultation. However, the number of the personnel is not enough, compared with the number of patients. Asymptomatic HIV participants were satisfied with Day Care service which was provided in many healthcare settings due to the courage gained and social support received such as instant milk for children, health-care counseling, occupational training, and financial aid. However, the effective Day Care service that is able to satisfy persons with HIV/AIDS must rely on governmental budgets. Not all patients with HIV/AIDS are satisfied with care or willing to take a long time in traveling to receive social support, obtain Day Care service, and take anti-retroviral therapy. Government, thus, should grant more budgets to provide Day Care services in every health service settings. Day care services should be provided with health promotion and self-monitoring methods in order to encourage persons with HIV infection to participate in self-care. Mental support and self-help group activities can also release emotional stress and increase willpower and hope. The service provision should cooperate NGOs activities and AIDS Networks and continuously evaluate the result of the supports and services.

Sustainable community resource and capacity

To promote persons with HIV/AIDS' access to sustainable community resources, the people in community should be prepared for the acceptance and the impartial distribution of locally organized funds. To encourage persons with HIV/AIDS to gain capacities in earning their living, the local government and multi-level organization should coordinate in fund projects. The projects of capability building for clients with HIV/AIDS and family should coordinate with a local fund raising. The project comprises the offering of occupational training, long-term monitoring and evaluation, including marketing. Thus, persons with HIV/AIDS can gain more income and decrease financial problems leading to an effortless access to health services.

To promote clients with HIV/AIDS in access to home and community care, the government should support capacity building for family and people in the community. Health volunteers who are family members and people in the community should be promoted with skill building of basic symptom caring, rehabilitation, and detection for patients with HIV/AIDS at home. People who work as health volunteers, especially both HIV volunteers and non-HIV infected volunteers, will be key persons who can provide effective care with coordination and collaboration with healthcare providers.

In order to support people living with HIV/AIDS continuously, those who endure the impact of AIDS like orphans or HIV-affected children should be taken into consideration for further support. As the AIDS disease brings about family and household problems on caregivers and children, the support or help should be offered in terms of proactive method emphasizing empowering them to rely on themselves. To empower

community capacity, both the government and private sectors should take part in raising an awareness of AIDS problems in community. The appropriate helps should include offering tangible and technical support for community to solve their problems. The local government and community will be the partnership with healthcare systems on taking responsibility for managing patients and family's problems as well as orphaned children. However, nowadays the social and economic welfare or aids for persons with HIV/AIDS are limited and do not cover those who cannot access the welfare services. The welfare strategic plans should therefore be established with proactive visions and respond to the distributed fund. The management of social funds should be evaluated for outcome criteria in order to sustain the helping fund and resources.

Consumers' rights and protection

According to HIV/AIDS patients' experiences about the failure in searching for alternative health service treatment, they had to pay for unqualified herbal drugs. As a result, the government should consider the herbal research as alternative medicine for persons with HIV/AIDS. The research should verify drugs' quality and standards by scientific methods. The research and development trials of alternative medicines should be reliable. The government should assemble community resources such as folk doctors, herbal doctors, and physicians to take part in community healthcare services in nearby areas. In addition, to monitor the quality assurance of private healthcare settings, there should be measures to protect consumers' fairness of cost of care and services. For instance, private sectors that are designated for public healthcare scheme and social security scheme for laborers and employees should be continuously investigated and

evaluated to ensure their quality and efficiency. Healthcare services in private sectors should also be controlled to guarantee reasonable costs. Finally, the government may manage and control the private hospitals through the national drug account supervision for reasonable reimbursement.

Universal healthcare coverage and minimum package

Negative stories of cost of care reflected the scenarios of the unfair health welfare arrangement. This inequality was also in contrast with the Health Policy's regulation in terms of improving and promoting the health of the general population to respond to people's expectations and needs. As a result, the healthcare policy should provide the system for financial protection against the cost of health and illness (World Health Organization, WHO, 2000a: 8) owing to the restriction of financing schemes including social security scheme and public healthcare scheme, which do not cover the prevention test such as blood test for CD4+ cell counts, anti-retroviral therapy, and drug addiction remedy. This issue, thus, should be thoroughly considered in order to ensure equality in access to health services for the underprivileged groups like poor people with HIV/AIDS. As a result, expenditure consideration should emphasize equality compared with expenditures for other chronic symptoms and the health promotion and encouragement, as well as disability and illness prevention. In addition, the standardized anti-retroviral therapy should be considered, while the universal healthcare coverage should afford patients a right to choose health service settings and networks.

Recently, 44% of AIDS infected laborors, came to receive health services at government and private health service settings (Division of Epidemiology, Ministry of

Public Health, 2002: 1). Furthermore, since almost all AIDS infected patients are laborers who have their right in the social security scheme, a Health Care Act should be launched to help laborers with HIV/AIDS to have better health, maintain effective work ability, and increase national production. Consequently, the social security fund of the Treatment Welfare Act consideration should include treatment to prevent opportunistic infection and to cover CD4+ cell count, routine health check-ups, and the appropriate anti-retroviral treatment. Moreover, the Social Security Act should extend the care in hospitals to include the home care under the criteria of treatment standard because the social security scheme's expense does not cover the continuous home care.

For the health promotion and illness prevention services, the monitoring of HIV disease progression and routine health check-ups are essential to prevent illness and opportunistic infection. Therefore, minimum package of health check-up of twice a year should be set as the standard of care. Measurement of immunity like CD4+ cell counts can be modified with low cost lab test in community care. For instance, the low-cost laboratory monitoring of total lymphocyte count can be used to replace CD+ cell count test (Sanne, 2001: 4-5). To prevent illness, chest x-ray for pneumonia and pulmonary tuberculosis should be considered in the healthcare coverage. Therefore, to monitor and evaluate the healthcare coverage for health promotion and illness prevention, the development of a minimum package of care and training for health personnel are required.

The proposed model of healthcare needs for asymptomatic HIV

The issues to be considered in policy making to improve healthcare for patients with HIV/AIDS can be explained in the forms of a model. The model of healthcare needs

should be developed under the condition of healthcare needs and the levels of disease progression of patients with HIV/AIDS. For instance, for the model of care for asymptomatic HIV clients (see Figure 2), clients need mental and emotional support, updated health information, as well as financial support to manage their lives. The component of service provision should be divided in many levels: home and community level, healthcare center, community hospital, and general hospital under the universal healthcare coverage scheme. The administration of health service network is in the form of top-down-and-bottom-up scheme arranged with coordination and continuous treatment and referral system in multi-sectors and with multi-levels with the participation of the government and NGOs. In addition, services for persons with asymptomatic HIV should emphasize how to encourage persons with HIV to gain self-efficacy, self-esteem, and empowerment by giving support about work in community, community participation, and social support so that patients would be accepted to live with the community.

Regarding special health promotion and illness prevention services, the low cost CD4+ cell count monitoring, annual health checkups, self-care knowledge training, and alternative therapies should be set up as standard care. The services are focused on clients' need. For equality and quality treatment, the standardized anti-retroviral therapy should be provided with CD4+ cell count less than 200. In addition, specific clinics in provincial hospital should be extended to community hospitals. The healthcare teams should include collaboration between doctors and nurse practitioners who have specific roles in providing care. Nurse practitioners have responsibility to monitor patients' drug intake and drug side effects in order to increase patients' drug adherence. Clients can

access nearby healthcare settings to reduce patients' expense of transportation. Hospitals should support group activities of AIDS clubs and encourage patients' self-care and health services in Day Care and special clinics including occupational training.

The proposed model of healthcare needs for symptomatic HIV

The model of healthcare needs for symptomatic HIV patients should be developed under the high need phase of care (see Figure 3). The issues to be considered for symptomatic HIV care are described in the form of a model that focuses on the management of clients with acute needs because of their severe vulnerability of health impairment and complicated problems. The component of services assembles the care providing in many levels: home and community levels, healthcare centers, community hospitals, and general hospitals under the universal healthcare coverage scheme. The health service network should be managed with the top-down-and-bottom-up coordination and the continuous treatment and referral system in multi-sectors and with multi-levels with the participation of the government and NGOs as formerly shown in Figure 2. Nevertheless, the care and treatment should place have more focuses on opportunistic infection treatment (OI) and anti-retroviral therapy (ARV). The rehabilitative health emphasizes the recovery from complications, viral load reduction and control, as well as immunity improvement. The health services and support are cooperated with the support for occupational training and family support in order to enable patients to return to work and earn their livings.

Service provisions emphasize the long-term care with the continuous family and community care in specific clinics and specific wards. Moreover, healthcare providers are key persons to encourage relatives or caregivers to take part in care. To empower caregivers in building up their capabilities, skill-training programs are basic requirement for home care. Relatives and volunteers can gain their ability and support from health services in order that they can monitor patients' drug intake and drug side effects. Continuous support from community healthcare and coordination with local NGOs is also the main element to promote the participation in hospice care for people living with the end stage of AIDS. Social welfare and financial reimbursement for HIV infected laborers can also be supported through social security fund.

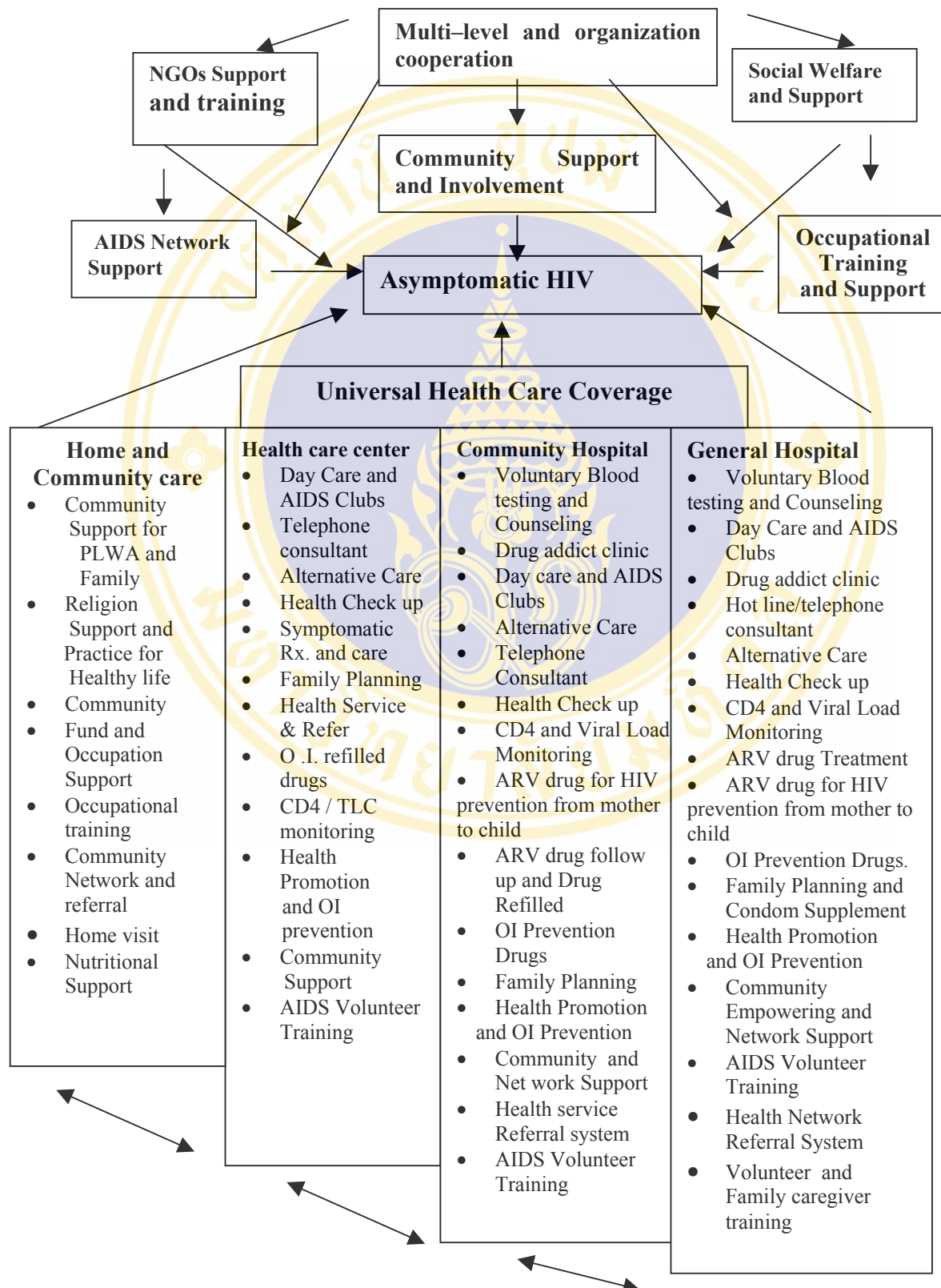
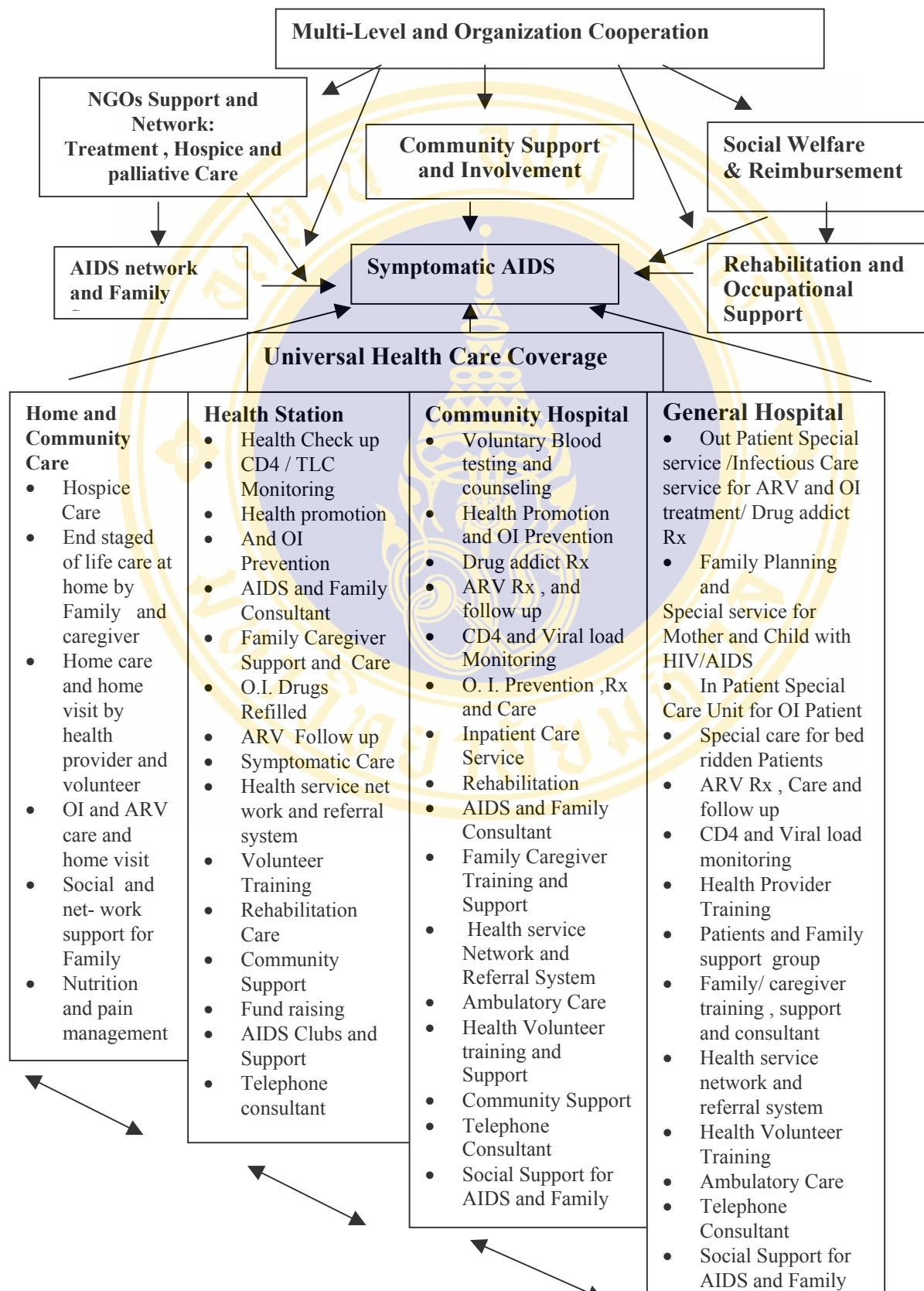
Figure2: Proposed Model of Health Care Needs For Asymptomatic HIV

Figure 3: Proposed Model of Health Care Needs for Persons with AIDS



CHAPTER VIII

CONCLUSION

This final chapter presents a summary of the study. Consequently, discussion of contribution to knowledge development is presented, followed by discussion of implication of research findings and implication for further studies. The chapter ends with features of healthcare policy that will address issues of access for persons with HIV/AIDS.

Summary of the study

The study of the National Plan and Policy for AIDS care concludes that the AIDS care policy lacks clear-cut management and distribution of resources and healthcare manpower in the multi-levels of healthcare systems. The tangibles plans of quality, standardized HIV/AIDS care and equal access to healthcare services are not set up. In addition, the models of holistic, continuum, and comprehensive care such as community-based care and home healthcare are not well implemented practically. Moreover, the study of the National AIDS Plan in developing countries such as South Africa, India, Pakistan, and Thailand also reveals that there is a lack of equality policy for HIV/AIDS treatment and care at a national level. Inadequate and unclear policies are major barriers and constraints to access effective care and treatment. The policies lack tangible strategic plans regarding resources mobilization, planning, advocacy skill, and understanding for human right issues to increase awareness on healthcare providers and people in community. Finally, the issues of right to health and right to

access to equal treatment and care still lack the affordable, available, appropriate method to prevent AIDS progression and evaluation on strategic planning.

Fifty participants in this study consisted of 30 females and 20 males with low income, and most of them had developed symptomatic AIDS, while few of them had recovered from opportunistic infection, living healthy while being HIV positive. Participants' experiences of accessing the healthcare system in different parts of Thailand display what people living with HIV/AIDS suffer with their illness and how they try to access healthcare in order to achieve the utilization of the healthcare system. Participants told the stories of experiences from the beginning of being informed of their HIV positive status until receiving the information of care and treatment in the healthcare arena. Each participant experienced healthcare system that affected their health in daily life as factors hindering or facilitating in access to health services. Participants have both negative and positive experiences in accessing healthcare systems.

Participants narrated their experiences in the healthcare system and described them in terms of structural constraints in the healthcare system, hindrances in access to healthcare and support, and existing quality healthcare: a small channel for healthcare participation to meet needs and expectation.

Structural constraints in the healthcare system

The participants described the structural constraints in healthcare systems in terms of service provision constraint, constraint of treatment and care, sub-standard healthcare environments, and constraint in healthcare coverage. The participants explained service provision constraints that blocked their access to quality, equity care and services. They described constraint of treatment and care that obstructed most of

their access to quality treatment such as anti-retroviral therapy and adequately continuous care. The sub-standard healthcare environments were composed of unqualified medicine and unscientific alternative therapy, lack of healthcare information to prevent illness and promote drug adherence, and lack of continuous and effective referral systems. These made participants unable to receive health promotion and prevention services to maintain their healthy status. The constraints of healthcare coverage that did not cover treatment of AIDS and investigation that impeded participants from receiving health promotion, symptom monitoring, and prevention of illness were also experienced. Persons with HIV/AIDS could not have benefits and gain facility from health welfare.

Hindrances in access to healthcare and support

Sufferers described the hindrances in access to care and support that were categorized as health personnel hindrance, personal weakness, as well as community and society hindrance. They confronted with government and healthcare providers who had prejudice and did not protect their human rights, preventing them from receiving healthcare and treatment in early stages of the disease. Personal weakness that was composed of self-refusal of care and support, economic prohibition, and poor health status were major hindrances of access to healthcare and support. Most of participants who had low-income and poor health status could not access to healthcare systems because they did not have the necessary basic needs to spend and utilize healthcare systems. The hindrances from family and community discrimination were barriers that blocked persons with HIV/AIDS in utilizing continuous healthcare systems and receiving adequate social-economic support and acceptance from society.

Existing quality healthcare: A small channel for healthcare participation to meet needs and expectation

The participants who were successful in accessing healthcare systems gained access through the opened gate of information and system for self-care development and used their own efforts to meet their needs and expectations. They could overcome suffering by empowering themselves leading to self-esteem and self-responsibility. They tried to seek various healthcare services to maintain their prolonged health such as being a member of HIV/AIDS club that supported them to gain access to specific programs of treatment and care such as anti-retroviral therapy project, home healthcare, and social support. Participants could gain benefits from the healthcare delivery such as ability to maintain self-development and ability to volunteer for healthcare development. Based on the experiences of persons with HIV/AIDS, the participants raised their needs and expectation to improve healthcare system in terms of equality and quality service provision with health promotion and illness prevention. They also requested for standardization and distribution of anti-retroviral therapy that was their major concern. Furthermore, the qualification of healthcare providers and quality of specific care were needed for consistent services. Moreover, the needs and expectations for equality healthcare coverage and consumer protection were recommended for every patient with HIV/AIDS. Their needs and expectations in healthcare would be the guideline in addressing health policy development.

All of healthcare needs of participants who are marginalized groups like HIV/AIDS are important evidence base from grass roots. Healthcare providers and policy makers can use them as the data assessment in order to develop a strategic plan

to improve access to care. The special needs of disadvantaged groups, those who are least able to seek services for geographic, political, social, or financial reasons, should be raised as the highest priority in the amendment of access to healthcare. Therefore, the proposed model of healthcare needs of persons with HIV/AIDS can be generated based on the collaboration of data base of the existing healthcare system and participants' needs. The proposed model of healthcare need is composed of equality, comprehensiveness, quality, effectiveness, and human protection at various healthcare settings, especially primary healthcare. The model can be used as guideline and applied for implementation of care provision of healthcare providers.

Contribution to knowledge development

Understanding the experience of suffering

The substantial knowledge gained from this study can contribute to nursing science in terms of understanding of the phenomena of suffering in the every day endeavor of disadvantaged groups, and establishing knowledge about health, healthcare system, and society that influence their health and illness in sufferers' perspectives (Melies, 1991: 111-113). The results of this study are particularly significant in illustrating the phenomenon of suffering within the environment of healthcare context, and exploring patient interaction with the healthcare system. This knowledge is derived from exploration of suffering, linking between suffering and constraint of the healthcare system and giving voice to patients with HIV/AIDS which contain accurate description of suffering caused by the healthcare system.

The definition of suffering in this study is consistent with the emotional response that occurs when an impending destruction of the persons is perceived.

Suffering continues until the treat of destruction has occurred or until the integrity of the person can be restored in some other manner (Cassel, 1991: 33). Furthermore, the experience of suffering in healthcare systems can be explained as a praxis theory of suffering that can be identified into two broad and divergent behavior stages of suffering: enduring and emotional suffering (Morse & Carter, 1996: 43-45).

Enduring is a strategy that enables the persons to go through the motions and to do what must be done (Morse, 2001: 50). This result also supports the evidence base of sufferers with HIV/AIDS who try to access healthcare to obtain care and treatment. In addition, they have enduring behavior to live because they want to protect their life and escape from danger of AIDS symptoms. On the other hand, persons with HIV/AIDS who have negative experience in access to healthcare have emotional suffering filled with sadness, and they try to escape emotional suffering and to access healthcare to overcome their illness (Morse & Doberneck, 1995: 277-280; Morse & Penrod, 1999: 145-150). They view healthcare system as factors that facilitate and hinder their access. Sufferers are HIV/AIDS patients who are in the vicious cycle of illness and struggle of access to care, treatment, and support from society and community.

The successful access to healthcare begins with how they try to seek healthcare and support including how they can get the benefits of their access and balance with the energy and the determination that they can attempt. Thus, the persons with HIV/AIDS who gain access to care are those who have undergone transition from suffering and have overcome suffering to be contributors. Moreover, when they achieve their goal, they contribute themselves for their members and people in society. In addition, according to the healthcare system constraint, hindrances in access to

support can make sufferers unable to overcome suffering. They cannot get the profit from the constrained healthcare and resources in community, leading to health deterioration and difficulty in maintaining healthy living.

Knowing how to assist those suffering

Nurse professionals are the healers of suffering. Understanding suffering and the responses and needs of those who suffer enhances nurses to establish the method to alleviate suffering (Roders & Cowles, 1997: 1048-1052). The story of persons with HIV/AIDS who suffer in the healthcare system gives the relevance of meaningfulness and treasures differences in life of people living with HIV/AIDS in access to the healthcare system. It helps explain the relationships among various factors in the macro system such as health systems, economics, politics, and society that influence the health and illness of human beings (Meleis, 1997: 106; Meleis, 1991:111-113; Newman, 1994: 155). This nursing knowledge moves from conceptualization of individuals to experiences of individuals, groups of disadvantaged people with HIV/AIDS, and it explains social equality as its primary objectives (Varcoe, 1996; Fraser, 1997 ; cited by Ddrevdahl, 1999: 10). The basic knowledge in this study can explore the meaning and consequences of inequitable access in the lives of people living with AIDS in terms of characteristics of sufferers and those who are empowered as contributors. This phenomenon can analyze and identify factors that impede and facilitate access to healthcare of sufferers (Stevens, 1992: 194). In addition, the inadequate and unequal healthcare system established by policy makers who were dominants affected health of persons with HIV/AIDS and communities (Stevens, 1989: 58).

The identification of healthcare needs to acknowledge the people with HIV/AIDS requires the turning point for improvement of healthcare services. This proposed model indicates to nursing action that will assure equitable access for disadvantaged groups. Furthermore, to improve the access to healthcare and support those who need to overcome suffering, there is need to reconstruct or to reform all the existing healthcare system (White, 1995: 85). This nursing knowledge will affect the position and visibility of nursing in policy planning and decision making about health issues. Thus, this knowledge will guide the healthcare policy planners in establishing the needed measure in terms of multi-disciplinary approach under the clients-focused care, involving community, society, and addressing equality, adequacy and quality of healthcare.

Ethical and moral perspectives of nursing

The knowledge in this study also enhances the ethical component of nursing that focuses on matters of obligation or what commitment needs to be done. The events of inequality in access to quality treatment and care, discrimination, and prejudices are problems of the violence of human rights in clients like the vulnerability group. This knowledge can examine the ethics of care and the ethics of justice in the healthcare system. As healthcare professionals, nurses are advocates who make an effort to help persons become healthy, and have quality of life. This evidence base enables nurses and the nursing organization to reflect consideration of ethics encompassed in the healthcare system providing health services to disadvantaged groups who cannot access quality health service with the same right as others. Therefore, this will guide nursing organizations to take action and have a voice to be involved in healthcare policy to serve consumers' needs (Chin & Krammer, 1999:5;

Stevens, 1992: 244-245; White, 1995: 85). Therefore, the study provides the verified data for nursing professionals and healthcare professional because it explores and exposes the construction of healthcare affecting people's health. Moreover, it will be the solid data for the nursing organization to enable all concerned to have a voice in healthcare provision and develop processes of health policy. The nursing organization should raise the issues of the rights and equal access in healthcare for persons with HIV/AIDS to be the ethical issues of national human rights. The results of this study can initiate the solutions of improving equal healthcare access for HIV/AIDS and other chronic diseases.

Implication and application of research findings

From the knowledge development with persons with HIV/AIDS who suffer, the researcher can gain the understanding of how the environment of healthcare, socially and economically, affects persons' health and illness. The method of narrative or story telling from persons with HIV/AIDS enhances the researcher to have empathic understanding of how they obtain care and survive. They have to push effort to overcome suffering. All of the participants are active persons but healthcare environment suppresses on them and hinders persons with HIV/AIDS, forcing them to struggle to receive healthcare services. Thus, the findings of this study have implications for nursing practice and nursing education as follows:

Implication for nursing practice and nursing administration

1. Client empowering and advocating

The good method to encourage individuals to participate in care and services continuously is client empowerment. This study can dwindle the theory- practice gap because it provides the relevant information for nursing intervention to solve the

existing problems of healthcare access. Sufferers had described what they had faced, as well as healthcare surroundings, as well as social, economic and political constraints in their search for healthcare (Mishler, 1986: 117-119). To express self-experience of health service access not only promotes persons with HIV/AIDS to release their suffering, but also helps them gain self-knowledge and recall their experience. Real-experienced story is the vivid data to obtain more understanding for healthcare providers and policy makers (Habermas, 1984: 216). Persons with HIV/AIDS also need their success and failure to be a testimony and become advantageous in health service system development for other clients with HIV/AIDS (Sakalys, 2000: 1472, Hall, 1999: 99).

Thus, service provision for empowering patients with HIV/AIDS is important for them to gain knowledge of self-care practice, self-monitoring of disease prevention and updated treatment, and care of AIDS. They can be empowered to cope with everyday struggle in healthcare and to find new solutions to maintain their health. From this study, after the interview, every participant was interested in their health and how to be healthy and free from illness. Thus, the investigator provided updated information and the knowledge that served the participants' need. Most of the participants could release the trouble kept in their mind. They felt happy that someone listened to their sad stories. One participant said after being interviewed:

I talked with you like we had something in our mind to exchange. You wanted to interview me for what I wanted to tell you. If you think it is useful, I will tell all of them to you. When the patients have severe illness, they want mental support and willpower. No need to give me the reimbursement. I can get the useful things from you. The information that you give me, I will try to practice. If I can do it, O.K; I will keep doing it. It looks like when we go to see the monk at a temple. When the monks gave us advice, this and that advice, then we listened and we felt very happy and joyful. Talking with you makes me happier than going to a temple and donate money to the monks. I feel happy because someone is listening to my story. I feel I can release my pressure. It is

better than sitting alone with sadness day by day, and think about the day I will die. You understand me! If you give me a thousand baht, I don't want it. I prefer talking with you. It makes me happy and have willpower....

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The empirical data from this study indicated characteristics of suffering and escape to overcome suffering. All the suffering process can change and be dynamic depending on the situation of health service and care provision and support. The important aspect that will enable client capability is to provide continuous empowerment in all the stages of the participants' illness in particular to promote sufferers to be overcome suffering. To encourage participants to overcome suffering and be a contributor will be the mutual goal of nurses and clients. As a result, effective counseling, updated information, comprehensive care, and appropriate resources are the matter to promote empowerment of persons with HIV/AIDS. However, the methods to solve the solution are focused in individuals; thus, the reconstruction and performance of good healthcare will be the goal for all underserved groups. According to participants' stories, the circumstances they faced make them disappointed with care and services they could not select in healthcare settings. Thus, nurses should be the advocates and facilitators for disadvantaged groups and promote them to access adequate, quality care. In addition, nurses should support them by being a mediator and coordinator and making a voice for these vulnerability groups.

2. Development of specialists in specific healthcare services

Healthcare staff and skill training in healthcare settings are necessary in extending specific services for persons with HIV/AIDS. Therefore, nurses should be promoted to be nurse practitioners and family nurses who provide comprehensive care for patients in the community and primary healthcare settings. The skill training program should contain advanced knowledge to care for patients with HIV/AIDS,

emphasizing both continuity of care and home healthcare. Nurses should be trained to be effective counselors for voluntary blood testing services and have responsibility to help clients cope with short-term response to HIV discovery. Acute follow-up is also important to help clients cope with their emotional problems. In addition, nurses should assess clients' needs and provide regular contacts to help the clients cope and accept their situation by designing with individuals anxiety management strategies that are suitable for their life. Moreover, referrals to needed resources and services could be made, and as the clients readiness permits. Nurses and healthcare teams should encourage persons with HIV/AIDS to gain knowledge about ways to live long and healthy. In community, multi-disciplinary of HIV/AIDS care and consultants for their family are required to promote continuity of care and rehabilitation. Furthermore, the skill training of basic treatment, health check-up, early detection, and immunity monitoring as well as symptomatic treatment is essential knowledge to care for those with symptomatic HIV to maintain their health.

3. Establishment of specific care and services for caregivers

Arrangement of special services at some healthcare setting is the challenge in promoting caregivers to involve in healthcare. From this study, caregivers are persons with HIV/AIDS who provide care for their relatives who have severe illness. Therefore, establishing a special ward to care for patients with HIV/AIDS and encourage caregivers to involve in care can reduce caregivers' stress and strain from their role. All caregivers will give support for each other because they have better understanding of their situation. The good benefit of special ward is that caregivers and persons with HIV/AIDS are not treated with discrimination or objection by other patients. Moreover, caregivers will be supported for skill training of care, mental

support from healthcare profession, and they should receive support from networks in the community.

4. Involvement of the healthcare team in continuity of care

The involvement of the healthcare team can improve health from healthcare settings to home care and community. From this study, the effective home healthcare provided by nurses and healthcare teams are valuable data in revealing the adequate, continuous care to improve health leading to recovery of persons with a chronic illness. Participants who receive home care can recover quickly and have treatment adherence, comprehensive care, and support for nutrition and materials for care. Thus, the policy of healthcare services should consider home care for persons with chronic illness and should be established in every healthcare setting.

5. Nurses are key persons of community healthcare

The extended role of nurses in public is important to better understand for persons with HIV/AIDS in their community. From this study, nurses are the care providers for people with HIV/AIDS. Nurses are good facilitators and advocates who can mobilize community resources to support persons with HIV/AIDS. Nurses are also key persons to motive community acceptance. Moreover, nurses can act as trainers in training for the skills of care and as mentors for community volunteers and NGOs volunteers to participate in home healthcare for persons with HIV/AIDS.

Implication for nursing education

1. Preparation for nursing education in the undergraduate level

The nursing curriculum should contain human rights and empowerment to enhance the knowledge of health. Problems of the disadvantaged groups should also be included in the curriculum of social, political, and health systems and

healthcare structures that have an impact on health and illness. The specific care of HIV/AIDS should be underlined especially therapeutic communication, empathic understanding, and protection of the client's right and advocacy. The nursing practice with chronic illness clients should be integrated in home and community care and all healthcare settings. In addition, the requirement of practice should include caring for patients with HIV/AIDS in the real situation.

2.Preparation for advance nursing profession to serve client's health need in community healthcare setting

From the findings of this study, the participants reflected the efficacy of health profession in community healthcare settings. Advanced nursing study in the diploma level and postgraduate level should be prepared to solve the problems of inadequate human resources in primary healthcare settings. The curriculum for preparing nurse practitioners and family nurses should contain healthcare system, health economic and case management, specific care and basic treatment for chronic illness, long term care and philosophy of humanity, and empowerment. The prepared strategies should focus on serving health professions who work in community hospitals and primary healthcare settings. The course of study should emphasize the research and development of healthcare systems, which guides the intervention and strategic plans for health policy.

Implication for the healthcare system

The findings of this study can be used as the issues of policy making to develop the proposed model of healthcare services to serve persons with HIV/AIDS's need. The models should contain the multi-disciplinary team approach with healthcare professionals, volunteers, people in community, family, and persons with HIV/AIDS.

The development of a referral system and effective collaborating networks for persons with HIV/AIDS should be integrated in the model with multi-sectoral and multi-level coordination. The proposed models of healthcare need for persons with HIV/AIDS are displayed in Figures Two and Three as the example in developing service provision under the condition of universal healthcare coverage. The models present the community and social involvement and collaborative care and resource mobilization in the healthcare system from community level to tertiary level. The model also describes special care and services that should be provided for patients with HIV/AIDS and risk groups such as drug addicts, those with mental health problems, women in reproductive services and family planning, as well as Day Care.

The effective implementation of healthcare policy needs client-healthcare provider collaboration with tangible monitoring and evaluation for continuous intervention. Thus, sufficient and safe healthcare environment, as well as mental and educational support, should be promoted to maximize healthcare providers' potential and decreases negative attitudes towards HIV/AIDS. Service provision should be established to encourage persons with HIV/AIDS and families to benefit from standard treatments and appropriate cares in communities, including access to quality counseling and health information to ensure patients' adherence with drug regimens. The resource allocation should be distributed and collaborated with effective referral networks and continuity of care and support among the multi-levels of the healthcare systems.

The effectiveness of continuity care at primary healthcare settings and nearby hospitals can reduce cost of care and cost outside of the healthcare system and facilitate persons with HIV/AIDS to access the healthcare system. The equality and

quality care provision should be provided as standard care and treatment at every healthcare setting with minimum healthcare package for every stage of HIV/AIDS patients. For instance, minimum package for symptomatic HIV should contain CD4+ cell count testing twice a year and routine health check-up with chest x-ray in order to monitor immunity and opportunistic infection of the lungs. Furthermore, symptomatic AIDS patients who have opportunistic infection need continuity of care at home. Thus, a package of home care should be provided in association with patients' condition and needs. Home care packages should include comprehensive care, promote drug adherence, and provide nutrition support and rehabilitation. Moreover, anti-retroviral drug regimens should be treated as parts of the package with the indication for treatment, monitoring for adverse drug effects, and promotion of drug adherence.

The national AIDS plan should address the unambiguous strategic plans to promote equal access to healthcare coverage of quality anti-retroviral treatments for all HIV/AIDS patients. The essential matters of care are the primary prophylaxis and the early diagnosis to prevent illness. Thus, there should be more mobilization of the number of anti-retroviral regimens and laboratory monitoring for funds and international support to build up human resources and infrastructures to deliver the standard treatment.

Implication for further studies

Limitation of this study

1. The participants who lived in different parts of Thailand had their own dialects and different cultures. Thus, the way they expressed their feelings and told the story depended on their culture, language, rapport, and trust of the researcher. Thus,

the participants became good participants who tried to tell their story in full details after the researcher could understand their dialect.

2. There were more single interviews than repeated interviews because the participants had health problems, and sometimes it was inconvenient to interview them twice. However, the data from other participants in the same healthcare setting could validate and verify the scientific adequacy of this study.

3. There were few specific groups of participants who participated in this study such as drug addicts because of the limitation of healthcare services.

4. This study indicated the gender differences because the numbers of participants who had willingness to participate in the project were more women than men. The proportion of women to men was 3:2. Thus, 30 women and 20 men were recruited in total, evenly distributed in the five regions.

Recommendations for further studies

1. Studies of healthcare experience and access to healthcare in specific groups such as women with HIV/AIDS, tuberculosis patients, women with abuse, drug addicts, prisoners, and other groups with chronic diseases as well as those with mental illness should be conducted in order to investigate the healthcare needs and factors that hinder their access to care.

2. There is also a need for action research to develop the continuity of the care model for person with HIV/AIDS suitable for community healthcare settings with multi-disciplinary approaches and community participation.

3. Studies of cost and effectiveness of care of patients with HIV/AIDS and other chronic diseases in terms of evidence-based assessment and intervention are also

needed. For instance, cost of care and anti-retroviral therapy, quality of life, symptom management, health promotion, and consequence of health and outcome related to the healthcare system should be further investigated in detail.

Recommendations for policy makers

This study used the critical theory giving HIV/AIDS sufferers the opportunity to voice their healthcare views and needs. HIV/AIDS sufferers who had difficulty in utilizing healthcare and their impacts related to health problems should be taken into consideration for improvement. The articulation of success in healthcare access of some patients with HIV/AIDS should empower others. Their stories provided the basic understanding of the healthcare system structures and discrimination that impeded others' healthcare access. The results of the study provide the evidence of and insights into how to improve the healthcare system by raising policy makers and leaders' awareness. The patients' rights to be healthy and to receive basic healthcare needs are critical in creating necessary changes to finally achieve appropriate healthcare policy. Thus, this study is an illustration of a way of knowing how to promote the utilization of healthcare services which are equal, adequate, and efficient for Thai people, especially the disadvantaged groups.

From the findings of this study, the problems that persons with HIV/AIDS mentioned and requested for equality of access to care are cost of care and the right to gain access to the health financing schemes. The issue of distribution of quality and adequate care and resources in community is also of a great concern. Thus, the addressed issues that can be recommended for a model healthcare service and can be

applied to the national policy and health system process based on this study are as follows:

1. Healthcare Act should be established to underline the universal coverage of health services in health promotion and illness prevention for persons with HIV/AIDS. Moreover, this Act should account for HIV/AIDS right which is equal to that of other chronic diseases.

2. Since almost all people with HIV/AIDS are low-educated laborers, the Social Security Fund of the Treatment Welfare Policy should include cost of illness prevention, health check-ups, and standardized anti-retroviral drug distribution. Moreover, the health financing policy should be extended to cover home healthcare and rehabilitation.

3. Continuing education and skill training for healthcare professionals to improve efficiency and quality of care for HIV/AIDS should be promoted in all health settings. Special staff training for anti-retroviral treatment in community care should be organized, and healthcare staff such as nurse practitioners, and family nurses should be promoted to provide close and continuum of care in the primary healthcare settings

4. Networking collaboration care system should be enacted to promote continuity of care. The primary healthcare service should provide one-stop services for counseling, Day Care, health check-up, immunity monitoring, and early detection more than purely symptomatic treatments. HIV volunteers and community volunteers should be encouraged to conduct activities and provide care for clients in the community.

5. Developing the standards of care and treatment and illness prevention is the first priority to improve equality of care. Research and development of anti-retroviral

drugs and the appropriate monitoring should be extended to community settings.

Providing alternative therapy and consumer protection for HIV/AIDS persons who choose traditional therapy should also be investigated, and the results and outcomes should be scientifically monitored.

6. Hospital and health setting accreditation and quality control should be monitored regularly. Provision of integrated clinics such as dope-addicted remedy, mental clinic, and HIV/AIDS care for AIDS patients should be arranged to improve better access in community care. The provision of care should contain a minimum healthcare package for health promotion and illness prevention including home care package for health recovery.

7. To promote better understanding of HIV/AIDS in community and society, the government should use proactive and empathic strategies for public relations. The support system should be coordinated with community resources such as NGOs, local government, labor-and-agriculture welfare, and occupation training for persons with HIV/AIDS and their family.

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Appendix A.

Personal Information Data

รหัส.....

วันที่.....

(บันทึกข้อมูลที่ได้จากการสัมภาษณ์และข้อมูลจากประวัติการรักษาที่โรงพยาบาล)

1. ข้อมูลส่วนบุคคล

1.1. อายุ.....ปี เพศ ☐ ชาย ☐ หญิง

ศาสนา.....

1.2. ที่อยู่.....

ภูมิลำเนาเดิม จังหวัด.....

สาเหตุที่ย้ายภูมิลำเนา.....

1.3. สถานภาพสมรส

☐ โสด ☐ คู่ ☐ หย่า แยก

สาเหตุของการหย่า แยก ม่าย.....

.....

1.4. ระดับการศึกษา

☐ ประถมศึกษา ☐ มัธยมศึกษาตอนต้น ☐ มัธยมศึกษาตอนปลาย ☐ อาชีวศึกษา

☐ ปริญญาตรี ☐ สูงกว่าปริญญาตรี ☐ อื่นๆ

ระบุ.....

1.5. อาชีพ ☐ รับจ้าง ☐ รับราชการ/รัฐวิสาหกิจ ☐ ค้าขาย

อื่น ๆ ระบุ.....

รายได้.....บาท/เดือน

1.6. ฐานะทางเศรษฐกิจ

☐ พอใช้ ☐ ไม่พอใช้ ☐ กู้หนี้ยืมสิน ☐ มีเงินเหลือเก็บ

2. ข้อมูลเกี่ยวกับครอบครัว

2.1. บทบาทในครอบครัวของผู้ให้ข้อมูล.....

สมาชิกที่อาศัยในครอบครัว มีจำนวน.....คน มีบุตร.....คน

ระบุ.....

2.2. ลักษณะของที่อยู่อาศัย

☐ บ้านเช่า ☐ มีที่อยู่เป็นของตนเอง ☐ อื่น ๆ

ระบุ.....

ค่าเช่า.....บาท/เดือน

2.3. ผู้ที่ช่วยเหลือค่าใช้จ่ายในครอบครัว.....

อาชีพ.....รายได้.....บาท/เดือน.

3. ข้อมูลเกี่ยวกับการใช้บริการสุขภาพ

3.1. ชื่อสถานพยาบาลที่อยู่ใกล้บ้านที่สุด.....

สถานพยาบาลที่ท่านไปใช้บริการสุขภาพในปัจจุบัน (รักษา HIV).....

ห่างจากบ้านเท่าไร.....

การเดินทางไปโรงพยาบาล โดย.....

☐ สะดวก ☐ ไม่สะดวก ค่าใช้จ่ายในการเดินทาง.....บาท

3.2. ท่านจ่ายค่ารักษาพยาบาลอย่างไร

☐ จ่ายค่ารักษาเอง ☐ บัตรสุขภาพ ☐ บัตรประกันสังคม

☐สวัสดิการข้าราชการ

☐ อื่น ๆ

ระบุ.....

4. ประวัติการรักษาที่แผนกผู้ป่วยนอก

4.1. อาการที่ผิดปกติมาตรวจในโรงพยาบาล.....

.....

4.2. โรคและภาวะแทรกซ้อนที่เป็นระยะ 3 เดือนที่ผ่านมา

.....

.....

4.3. ผลการตรวจระดับภูมิคุ้มกันเม็ดเลือดขาว(CD4).....

อื่นๆ.....

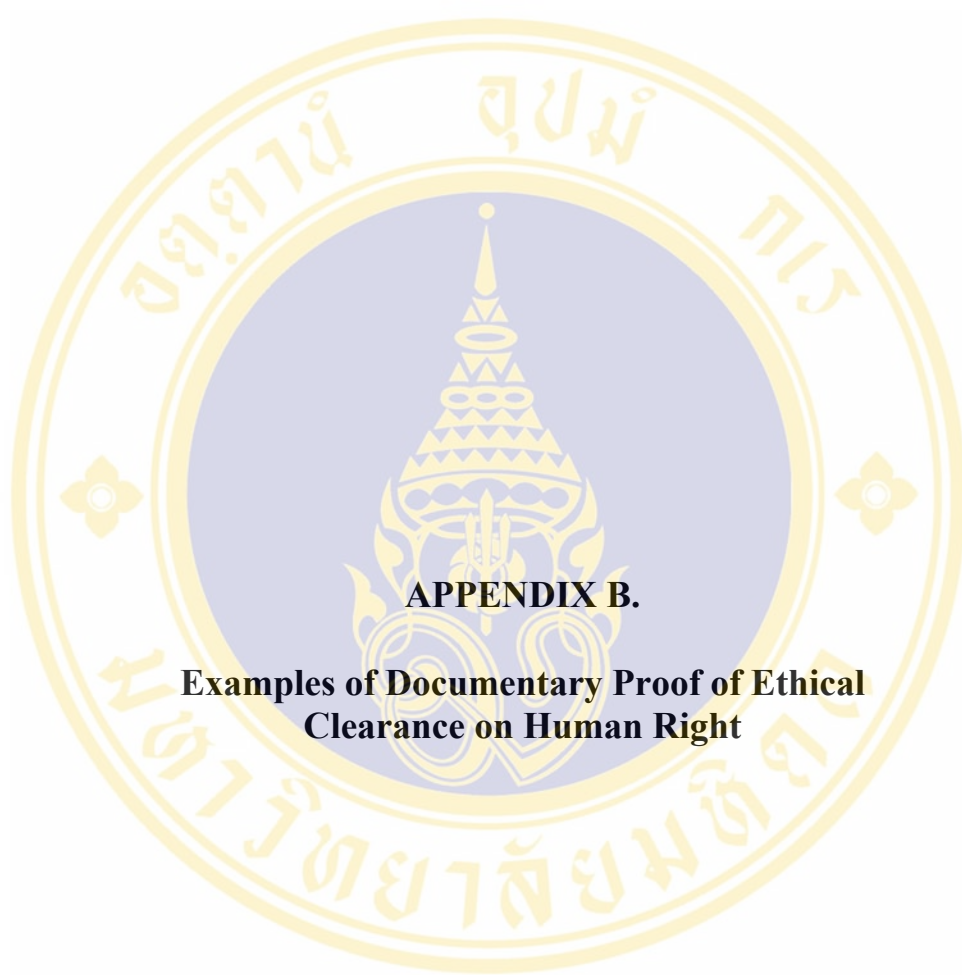
4.4. การรักษาที่ได้.....

.....

.....

4.5. ประวัติรักษา HIV/AIDSตามสถานพยาบาลต่างๆ

ระบุ.....





คณะแพทยศาสตร์ โรงพยาบาลรามาธิบดี มหาวิทยาลัยมหิดล

ถนนพระราม 6 กทม. 10400

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Documentary Proof of Ethical Clearance Committee on Human Rights

Related to Researches Involving Human Subjects

Faculty of Medicine, Ramathibodi Hospital, Mahidol University

No. 457/2001(I)

Title of Project : Improve Health Care for HIV/AIDS in Thailand: Learning from Those Who Suffer

Protocol Number : ID 07-44-05

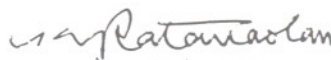
Principal Investigator : Miss. Duangkamol Wattradul

Name of Department : Department of Nursing

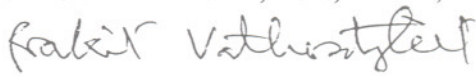
The aforementioned Project and informed consent have been reviewed and approved by Committee on Human Rights Related to Researches Involving Human Subjects, based on the Declaration of Helsinki.

Signature of Chairman

Committee on Human Rights Related to
Researches Involving Human Subjects


.....
Prof. Krisada Ratana-olarn, M.D., FRCST, FICS.

Signature of Dean


.....
Prof. Prakrit Vathesatogkit, M.D., ABIM., FRCP.

Date of Approval

July 18, 2001

Appendix C. Interview Guide

(Thai version)

แนวคำถามในการสัมภาษณ์

รหัส #.....ครั้งที่.....

วันที่สัมภาษณ์.....

ดิฉันมีความสนใจที่จะศึกษาว่าผู้ป่วยที่ติดเชื้อ HIV มีความรู้สึก และความคิดเห็นอย่างไรบ้างในประสบการณ์ของการไปใช้บริการสุขภาพในสถานบริการของรัฐ แนวคำถามดังกล่าวจะเป็นแนวทางในการที่จะให้ผู้ป่วยเล่าเรื่องราวต่างๆ เกี่ยวกับการไปใช้บริการสุขภาพที่ได้ประสบมา

1. ตั้งแต่ท่านได้รับเชื้อ HIV ท่านเคยไปใช้บริการสุขภาพที่ไหนบ้าง
2. ขอให้เล่าให้ฟังว่าบริการที่ท่านไปใช้เป็นอย่างไรบ้าง
 - 2.1. การให้คำปรึกษา
 - 2.2. การรักษาที่แผนกผู้ป่วยนอก
 - 2.3. การให้การดูแลโดยพยาบาล
 - 2.4. การรักษาตัวในโรงพยาบาล
 - 2.5. การได้รับความช่วยเหลือจากโรงพยาบาล เช่น แผนกสังคมสงเคราะห์และอื่นๆ
3. ท่านทราบถึงการใช้สิทธิ ในการใช้บริการในโรงพยาบาลอย่างไรบ้าง
 - 3.1. ท่านใช้สิทธิอะไรในการมาใช้บริการด้านการรักษาที่นี่(โรงพยาบาล หรือสถานบริการสุขภาพ)
 - 3.2. ท่านคิดว่าสิทธิที่ท่านได้รับในการรักษาเท่าเทียมกับสิทธิต่างๆหรือไม่ อย่างไร
 - 3.3. ท่านคิดว่าท่านได้ผลประโยชน์อะไรบ้างจากการใช้สิทธิในการรักษาดังกล่าว
 - 3.4. ท่านคิดว่าสิทธิการรักษาที่ท่านใช้มีข้อจำกัดอะไรบ้าง
 - 3.5. ท่านคิดว่าสิทธิในการรักษาที่ท่านได้รับควรเป็นอย่างไร
4. ปัญหาในการใช้บริการสุขภาพมีอะไรบ้าง

ท่านต้องการความช่วยเหลือด้านใดบ้าง อย่างไร

 - 4.1. ค่าใช้จ่ายในการรักษา เดินทาง ความเป็นอยู่
 - 4.2. คุณภาพและความเท่าเทียมของการรักษา
 - 4.3. คุณภาพและความครอบคลุมของการให้บริการพยาบาล
 - 4.4. ความเหมาะสมและคุณภาพของผู้ให้บริการ
5. ขอให้ท่านช่วยเล่าปัญหาที่ท่านได้รับเมื่อมาใช้บริการด้านการรักษาในโรงพยาบาล/ ศูนย์บริการสุขภาพ

ท่านมีวิธีการแก้ปัญหาที่เกิดขึ้นเหล่านี้หรือไม่ อย่างไร
6. ขอให้ท่านเล่าประสบการณ์ที่ประสบความสำเร็จในการมาใช้บริการสุขภาพ ท่านคิดว่าท่านมีวิธีการอย่างไรในการประสบความสำเร็จ หรือมีใครบ้างที่ช่วยเหลือท่าน

7. ท่านคิดว่าผู้ป่วยที่ติดเชื้อและผู้ป่วยเอดส์ควรได้รับการดูแลอย่างไรบ้าง ในด้านต่างๆ ดังนี้
ท่านคาดหวังและต้องการในบริการด้านสุขภาพที่มีกับท่านอย่างไร และคิดว่าใครมีหน้าที่รับผิดชอบหรือจัดการ
- 7.1. ด้านการส่งเสริมสุขภาพและป้องกันโรคแทรกซ้อน
 - 7.2. ด้านการดูแลรักษาในระยะแรกและระยะเจ็บป่วยเรื้อรัง
 - 7.3. ด้านการฟื้นฟูสภาพร่างกาย
 - 7.4. การช่วยเหลือทางสังคม
8. ท่านจ่ายค่ารักษาและบริการสุขภาพอย่างไรบ้าง ท่านคิดว่าค่าใช้จ่ายแพงสำหรับท่านหรือไม่
9. ท่านคิดว่าค่าใช้จ่ายในการบริการสุขภาพที่คิดว่าเป็นธรรมและเหมาะสมสำหรับท่านควรเป็นอย่างไร



Appendix C. Interview Guide (English Version)

Code #.....

No. of interview.....

Date.....

I am interested in what persons with HIV/AIDS infection feel or perceive about their experiences in going to use the health services in hospital (or health settings). These following questions will use as a guideline to explore the experiences of HIV/AIDS in accessing health care systems.

1. After you have HIV infection and when you are sick where did you go to receive care and treatment?
2. What has it been like for you to get health care?
Tell me about the health services that you have got.
 - 2.1. Counseling services
 - 2.2. Out patient treatment and care
 - 2.3. Nursing care services
 - 2.4. In patient admission services
 - 2.5. Support services
3. What do you know about your rights in health services?
 - 3.1. What rights do you have?
 - 3.2. Do you think it is fair for you when you use this right for using health care services and compare with others?
 - 3.3. What benefit do you have when you have rights in health services?
 - 3.4. What is the limitation of your rights?
 - 3.5. What your rights in using health care can be?
4. What do you identify as barriers to seeking help?
Please tell me what kind of support you need?
 - 4.1 Financial problem, cost of treatment, transportation
 - 4.2. The quality and equity of treatment, comprehensive care and services
 - 4.3. The equality and justification of health care providers
5. Please tell me about your problems when you have experiences health care services? How did you solve these problems?
6. Please tell me about your satisfaction when you have experiences health care services? What are the factors that support you?
7. Please tell me what kinds of health care services should be provided for people with HIV/AIDS? What expectations of care do you need? Who should take responsibility to this work?
 - 7.1. Health promotion and prevention for complication
 - 7.2. Treatment in early stage and chronic stage
 - 7.3. Rehabilitation/ Social Support
8. How do you pay for health care services? Are they too costly for you?
9. What is the cost of care and services that it is fair and appropriate for you?

Appendix D. Fieldnote Guide (Thai version)

รหัส #.....

วันที่.....

สถานที่.....เวลา.....

1. ผู้ให้สัมภาษณ์

- 1.1. ลักษณะทั่วไป
- 1.2. วิธีการที่ได้มาสัมภาษณ์
- 1.3. สัมพันธภาพกับผู้สัมภาษณ์
- 1.4. สัมพันธภาพกับผู้ให้ข้อมูลคนอื่นๆ

2. สถานการณ์ทางด้านสังคม

- 2.1. ลักษณะของสถานที่สัมภาษณ์/ โรงพยาบาล/ บ้าน
- 2.2. สิ่งแวดล้อมของสถานที่
- 2.3. สิ่งแวดล้อมจากบุคคล / ความร่วมมือ

3. สภาพอารมณ์ของผู้ให้สัมภาษณ์ในขณะสัมภาษณ์

- 3.1. ระยะเวลาของการสัมภาษณ์
- 3.2. ความเหมาะสมกับเวลาส่วนตัว
- 3.3. การให้ความร่วมมือในการสัมภาษณ์

4. การสื่อสารในขณะสัมภาษณ์

- 4.1. Non verbal communication
- 4.2. Tone of voice/ Feeling
- 4.3. ท่าที/ การไว้วางใจ/ ท่าทีกระตือรือร้นในการเล่าเรื่อง
- 4.4. การได้สะท้อนคิด
- 4.5. การบรรลุเป้าหมายในการเล่าเรื่อง
- 4.6. ท่าทีความพึงพอใจ/ อารมณ์ หลังจากเล่าเรื่อง

5. ปฏิกริยาของผู้วิจัยในขณะสัมภาษณ์

- 5.1. ความรู้สึก / อารมณ์
- 5.2. การสะท้อนกลับ และการรับฟังเรื่องราว

6. การประเมินผลหลังการสัมภาษณ์

- 6.1. ความประทับใจผลงานในการสัมภาษณ์
- 6.2. การเปรียบเทียบกับสัมภาษณ์ผู้ให้ข้อมูลคนอื่นๆ
- 6.3. ประสิทธิภาพของวิธีการสัมภาษณ์

Appendix D.

Fieldnote Guide (English version)

Code #.....

Date

Place.....Time.....

1. Participant

- 1.1.General appearance
- 1.2.How recruited for sample
- 1.3. Relationship to Researcher
- 1.4. Relationship to other participants

2. Social Situation/ context

- 2.1.Characteristic of setting/ hospital / house
- 2.2.Environment of setting
- 2.3.Environment of person in setting / cooperation

3. Temporal context of participation

- 3.1.Time and duration
- 3.2. Fit for daily schedule
- 3.3.Participation in interview

4. Communication during interview process

- 4.1.Non verbal communication
- 4.2.Tone of voice/ Feeling
- 4.3.Trust/ rapport/ Motivation in telling story
- 4.4.Reflection
- 4.5.Achievement of story telling
- 4.6. Satisfaction / emotion / feeling after telling story

5. The researcher action /reaction

- 5.1.Feeling /emotion
- 5.2. Reflection and listening

6. Evaluation of interview

- 6.1.Impression of interview
- 6.2.Comparison with other participant interview
- 6.3.Effectiveness of interview procedure





ที่ ทม 0802.01(สร)/ 1190

บัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล
คณะแพทยศาสตร์ศิริราชพยาบาล
ตึกจุลชีวินวิทยา ชั้น 4 2 ถนนพหลโยธิน
เขตบางกอกน้อย กรุงเทพฯ 10700
โทร.419-7060 โทรสาร 411-2002

29 พฤษภาคม 2544

เรื่อง ขอความอนุเคราะห์ให้นักศึกษาได้มาเก็บข้อมูล เพื่อประกอบการทำวิทยานิพนธ์
เรียน ผู้อำนวยการโรงพยาบาลจุฬาลงกรณ์ สภากาชาดไทย
สิ่งที่ส่งมาด้วย แบบสัมภาษณ์

ด้วย นางสาวดวงกมล วัตรคุณ นักศึกษามหาวิทยาลัยมหิดล หลักสูตร
พยาบาลศาสตรบัณฑิต คณะพยาบาลศาสตร์ กำลังทำวิทยานิพนธ์เรื่อง “การพัฒนาการดูแลสุขภาพสำหรับผู้ติดเชื้อและผู้ป่วย HIV/AIDS ในประเทศไทย : การเรียนรู้จากผู้ติดเชื้อ HIV/AIDS ที่ประสบความสำเร็จ” อยู่ใน
ความควบคุมของ ผศ.ดร.ศิริอร สิ้นธุ ซึ่งในการศึกษาวิจัยครั้งนี้ นักศึกษามีความประสงค์จะเก็บข้อมูลจากผู้ติดเชื้อ
HIV/ผู้ป่วยเอดส์ อายุมากกว่า 15 ปี ทั้งเพศชายและหญิงที่รับการรักษาที่แผนกผู้ป่วยนอก ตึก ภปร. แผนกผู้ป่วยใน
อายุรศาสตร์ โรงพยาบาลจุฬาลงกรณ์ โดยใช้วิธีการสัมภาษณ์เจาะลึกด้วยตนเอง ตั้งแต่วันที่ 1 พฤษภาคม 2544
ถึงวันที่ 31 ธันวาคม 2544

บัณฑิตวิทยาลัย จึงขอความกรุณาจากท่านโปรดอนุเคราะห์ให้นักศึกษาได้เก็บข้อมูลเพื่อ
ประกอบการทำวิทยานิพนธ์ ตามที่เห็นสมควรด้วย จักเป็นพระคุณยิ่ง

ขอแสดงความนับถือ

(ศาสตราจารย์อำนวยการ วิชาพันธุ)

รองคณบดีฝ่ายวิชาการ ปฏิบัติราชการแทน
คณบดีบัณฑิตวิทยาลัย

ติดต่ออาจารย์ผู้ควบคุมวิทยานิพนธ์ : ผศ.ดร.ศิริอร สิ้นธุ
โทร.412-8417 โทรสาร 412-8415



บัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล
คณะแพทยศาสตร์ศิริราชพยาบาล
ตึกจุฬาลงกรณ์ ชั้น 4 2 ถนนพหลโยธิน
เขตบางกอกน้อย กรุงเทพฯ 10700
โทร.419-7060 โทรสาร 411-2002

ที่ ทม 0802.01(สร)/ 1191

29 พฤษภาคม 2544

เรื่อง ขอความอนุเคราะห์ให้นักศึกษาได้มาเก็บข้อมูล เพื่อประกอบการทำวิทยานิพนธ์
เรียน ผู้อำนวยการโรงพยาบาลจังหวัดสุรินทร์
สิ่งที่ส่งมาด้วย แบบสัมภาษณ์

ด้วย นางสาวดวงกมล วัฒราดุลย์ นักศึกษามหาวิทยาลัยมหิดล หลักสูตร
พยาบาลศาสตรบัณฑิต คณะพยาบาลศาสตร์ กำลังทำวิทยานิพนธ์เรื่อง “การพัฒนาการดูแลสุขภาพสำหรับผู้ติดเชื้อและผู้ป่วย HIV/AIDS ในประเทศไทย : การเรียนรู้จากผู้ติดเชื้อ HIV/AIDS ที่ประสบความสำเร็จ” อยู่ใน
ความควบคุมของ ผศ.ดร.ศิริอร สันธุ ซึ่งในการศึกษาวิจัยครั้งนี้ นักศึกษามีความประสงค์จะเก็บข้อมูลจากผู้ติดเชื้อ
HIV/ผู้ป่วยเอดส์ อายุมากกว่า 15 ปี เพศชายและหญิงซึ่งเข้ารับการรักษาตัวแผนกผู้ป่วยใน และมารับบริการ
สุขภาพที่แผนกผู้ป่วยนอก โรงพยาบาลจังหวัดสุรินทร์ โดยใช้วิธีการสัมภาษณ์เจาะลึกด้วยตนเอง ตั้งแต่วันที่ 1
พฤษภาคม 2544 ถึงวันที่ 31 ธันวาคม 2544

บัณฑิตวิทยาลัย จึงใคร่ขอความกรุณาจากท่านโปรดอนุเคราะห์ให้นักศึกษาได้เก็บข้อมูลเพื่อ
ประกอบการทำวิทยานิพนธ์ ตามที่เห็นสมควรด้วย จักเป็นพระคุณยิ่ง

ขอแสดงความนับถือ

(ศาสตราจารย์อำนวยการ ติฐาพันธ์)

รองคณบดีฝ่ายวิชาการ ปฏิบัติราชการแทน
คณบดีบัณฑิตวิทยาลัย

ติดต่ออาจารย์ผู้ควบคุมวิทยานิพนธ์ : ผศ.ดร.ศิริอร สันธุ

โทร.412-8417 โทรสาร 412-8415



APPENDIX F

**เอกสารชี้แจงข้อมูล/คำแนะนำแก่ผู้เข้าร่วมโครงการ
(Patient Information Sheet)**

ชื่อโครงการ การพัฒนาการดูแลสุขภาพสำหรับผู้ติดเชื้อและผู้ป่วย HIV/AIDS ในประเทศไทย :
การเรียนรู้จากผู้ติดเชื้อ HIV/AIDS ที่ประสบความสำเร็จ

ชื่อผู้วิจัย นางสาว ดวงกมล วัตราคูลย์ นักศึกษาปริญญาเอก คณะพยาบาลศาสตร์
มหาวิทยาลัยมหิดล

สถานที่วิจัย แผนกผู้ป่วยนอกและ ที่หอผู้ป่วย โรงพยาบาล.....

ผู้สนับสนุนงานวิจัย คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล

ความเป็นมาของโครงการ

เนื่องจากในปัจจุบันมีผู้ติดเชื้อและผู้ป่วย HIV/AIDS เพิ่มขึ้นมากในขณะที่ยังขาดการให้บริการดูแลสุขภาพที่มีจำกัด ดังนั้นในการจัดระบบบริการสุขภาพให้แก่ผู้ติดเชื้อและผู้ป่วย HIV/AIDS ให้ได้รับบริการสุขภาพที่ครอบคลุม เท่าเทียมและมีประสิทธิภาพ จำเป็นต้องได้ข้อมูลจากผู้รับบริการสุขภาพซึ่งเป็นผู้ที่มีประสบการณ์โดยตรงเกี่ยวกับลักษณะของบริการที่ได้รับ สิทธิของท่านในการใช้บริการสุขภาพ ค่าใช้จ่ายในด้านบริการสุขภาพ อุปสรรคในการเข้าถึงบริการสุขภาพ เพื่อที่จะได้นำข้อมูลดังกล่าวมาเป็นข้อมูลพื้นฐานในการจัดทำข้อเสนอแนะนโยบายสุขภาพ เพื่อปรับปรุงระบบบริการสุขภาพสำหรับผู้ติดเชื้อและผู้ป่วย HIV/AIDS ให้เท่าเทียมและมีคุณภาพต่อไป

วัตถุประสงค์ 1. ศึกษาประสบการณ์ในการใช้บริการสุขภาพของผู้ติดเชื้อและผู้ป่วย HIV/AIDS

2. ได้ข้อมูลในการจัดทำนโยบายสุขภาพเพื่อปรับปรุงระบบบริการสุขภาพในประเทศไทย

รายละเอียดที่จะปฏิบัติต่อผู้เข้าร่วมโครงการ

ผู้วิจัยจะได้รับอนุญาตให้สัมภาษณ์ผู้เข้าร่วมโครงการจากพยาบาลที่รู้จักกับผู้ติดเชื้อ HIV/AIDS ผู้วิจัยจะสัมภาษณ์และอัดเทปเมื่อ ผู้เข้าร่วมโครงการอนุญาตและยินยอมให้สัมภาษณ์และอัดเทป ซึ่งใช้เวลา 45-60 นาที โดยจะขออนุญาตสัมภาษณ์ซ้ำเพื่อขอข้อมูลเพิ่มเติมหรือให้ผู้เข้าร่วมโครงการร่วมตรวจสอบข้อมูลที่สัมภาษณ์แล้ว โดยสถานที่ เวลานั้นคหามาข ในการสัมภาษณ์ขึ้นอยู่กับความสะดวกของผู้เข้าร่วมโครงการ

ประโยชน์หรือผลข้างเคียงที่จะเกิดกับผู้เข้าร่วมโครงการ

ผู้เข้าร่วมโครงการจะไม่เกิดผลข้างเคียงในการวิจัยครั้งนี้ แต่จะได้รับประโยชน์จากงานวิจัยนี้ในอนาคต เนื่องจากจะนำไปใช้เป็นข้อเสนอในการจัดทำนโยบายสุขภาพให้เท่าเทียมแก่ผู้ติดเชื้อและผู้ป่วย HIV/AIDS

การเก็บข้อมูลเป็นความลับ

ข้อมูลต่างๆที่ได้รับจากการสัมภาษณ์จะถูกเก็บรักษาเป็นความลับ และจะเปิดเผยเมื่อได้รับอนุญาตจากผู้เข้าร่วมโครงการ จะไม่มีการระบุชื่อในการบันทึกเทป และในรายงานสรุป จะใช้รหัสแทนและเอกสารหมายเลขรหัสจะถูกเก็บไว้เป็นความลับ และจะถูกทำลายเมื่อสิ้นสุดการวิจัย

**หนังสือยินยอมโดยได้รับการบอกกล่าวและเต็มใจ
(Informed Consent Form)**

ชื่อ โครงการ การพัฒนาการดูแลสุขภาพสำหรับผู้ติดเชื้อและผู้ป่วย HIV/AIDS ในประเทศไทย :

การเรียนรู้จากผู้ติดเชื้อ HIV/AIDS ที่ประสบความทุกข์

ชื่อผู้วิจัย นางสาว ดวงกมล วัตราคุลย์

ชื่อผู้ถูกวิจัย

อายุ เลขที่เวชระเบียน.....

คำยินยอมของผู้ที่ถูกวิจัย

ข้าพเจ้า นาย / นาง/ นางสาว ได้ทราบรายละเอียดของโครงการวิจัยตลอดจนประโยชน์ และข้อเสี่ยงที่จะเกิดขึ้นต่อผู้ยินยอมตนให้ทำวิจัยจากผู้วิจัยแล้วอย่างชัดเจน ไม่มีสิ่งใดปิดบังซ่อนเร้นและยินยอมให้ทำการวิจัยในโครงการที่มีชื่อข้างต้น และข้าพเจ้ารู้ว่าถ้ามีปัญหาหรือข้อสงสัยเกิดขึ้น ข้าพเจ้าสามารถสอบถามผู้วิจัยได้ และข้าพเจ้าสามารถไม่เข้าร่วมโครงการวิจัยนี้เมื่อใดก็ได้ โดยไม่มีผลกระทบต่อการรักษาที่ข้าพเจ้าพึงได้รับ นอกจากนี้ผู้วิจัยจะเก็บข้อมูลเฉพาะเกี่ยวกับตัวข้าพเจ้าเป็นความลับและจะเปิดเผยได้เฉพาะในรูปแบบที่สรุปผลการวิจัย การเปิดเผยข้อมูลเกี่ยวกับตัวข้าพเจ้าต่อหน่วยงานต่างๆ ที่เกี่ยวข้อง กระทำได้เฉพาะกรณีจำเป็นด้วยเหตุผลทางวิชาการเท่านั้น

ลงชื่อ.....(ผู้ยินยอมตนให้ทำวิจัย)

.....(พยาน)

.....(พยาน)

วันที่.....

คำอธิบายของแพทย์หรือผู้วิจัย

ข้าพเจ้าได้อธิบายรายละเอียดของโครงการ ตลอดจนประโยชน์ของการวิจัย รวมทั้งข้อเสี่ยงที่อาจเกิดขึ้นแก่ผู้ยินยอมตนให้ทำวิจัยทราบแล้วอย่างชัดเจน โดยไม่ปิดบังซ่อนเร้น

ลงชื่อ.....(แพทย์หรือผู้วิจัย)

วันที่.....

หมายเหตุ : กรณีผู้ยินยอมตนให้ทำวิจัยไม่สามารถอ่านหนังสือได้ ให้ผู้วิจัยอ่านข้อความในใบยินยอมฯนี้ให้แก่ผู้ยินยอมตนให้ทำวิจัย ฟังจนเข้าใจดีแล้ว และให้ผู้ยินยอมตนให้ทำวิจัยลงนามหรือพิมพ์นิ้วหัวแม่มือรับทราบในการให้ความยินยอมดังกล่าวข้างต้นด้วย

BIOGRAPHY

NAME	Miss Duangkamol Wattradul
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