

**COPING PROCESS OF
PERSONS WITH LONG-TERM HIV INFECTION**



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COPING PROCESS OF PERSONS WITH LONG-TERM HIV INFECTION

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ABSTRACT

People with long-term HIV infection are individuals who have lived with HIV longer than usual. It is still unknown how these groups of Thai people cope with their experience of HIV/AIDS. This study aimed to explore how long-term HIV-infected Thai people cope with the problems or events related to the infection. The qualitative research method of grounded theory was used. The participants consisted of 20 Thai people who had been infected with HIV for ten or more years. In-depth interviews were the main method of data collection. Constant comparison and a coding process were the basic analysis methods.

The study findings illustrated the coping process among long-term HIV-infected Thai people. It was entitled "The process of fighting to live normally with HIV infection." It was a process in which the participants had to struggle against the suffering and many problems created from having HIV infection in order to achieve a state of living normally. The process consists of four consecutive stages—Flight, Pulling oneself together to fight, Fighting for existence, and Living normally. In the flight stage, the participants avoided facing or ran away from the situations related to the infection. The second stage, pulling oneself together to fight, was a period in which the participants turned themselves from flight to a ready state to fight for living. The third stage, fighting for existence, was a stage in which the participants worked very hard to overcome many events or difficulties in order to continue their lives and attain their purposes in living. Finally, living normally was a state in which they perceived themselves and went on with lives as normal persons living in the society. The findings also reveal that the perception of HIV/AIDS among these people continuously changed from a negative to a positive view. Each stage of the process was analyzed in terms of causal conditions, contextual conditions, intervening conditions, action and interaction strategies, and consequences.

This substantive theory offers a new insight into the coping process of long-term HIV-infected people. It can be used as a guideline to develop an intervention program to facilitate the ability of HIV-infected people to cope effectively with HIV infection from the time they first learn of their infection. The program should be a course of continual and dynamic actions that should be adjusted to the dynamic conditions of the HIV-infected people. Future research should be aimed at evaluating the effectiveness of the program.

KEY WORDS: COPING PROCESS / FIGHTING / LIVING NORMALLY / LONG-
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กระบวนการเผชิญปัญหาของผู้ติดเชื้อเอชไอวีที่มีชีวิตยืนยาว (COPING PROCESS OF PERSONS WITH LONG-TERM HIV INFECTION)

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บทคัดย่อ

ผู้ติดเชื้อเอชไอวีที่มีชีวิตยืนยาวเป็นผู้ที่สามารถมีชีวิตอยู่กับเชื้อเอชไอวีได้นานกว่าเกณฑ์เฉลี่ยโดยทั่วไป ประสบการณ์การเผชิญปัญหาของผู้ติดเชื้อเอชไอวีชาวไทยที่มีชีวิตยืนยาวเป็นอย่างไร ยังไม่มีรายงานการศึกษาที่กล่าวถึง การศึกษาครั้งนี้จึงมีวัตถุประสงค์เพื่อค้นหาว่า ผู้ติดเชื้อเอชไอวีชาวไทยที่มีชีวิตยืนยาวเผชิญกับการติดเชื้อ ปัญหา และเหตุการณ์ต่างๆอันสืบเนื่องจากการติดเชื้ออย่างไร ระเบียบวิธีวิจัยที่ใช้ในการศึกษาคือการวิจัยเชิงคุณภาพแบบการสร้างทฤษฎีจากข้อมูลพื้นฐาน ข้อมูลหลักได้จากการสัมภาษณ์เจาะลึกผู้ติดเชื้อเอชไอวีชาวไทยที่ติดเชื้อมานานสิบปีขึ้นไป จำนวน 20 คน วิเคราะห์ข้อมูลโดยใช้กระบวนการให้รหัสร่วมกับการเปรียบเทียบข้อมูล

ผลการศึกษาแสดงให้เห็นกระบวนการเผชิญปัญหาของผู้ติดเชื้อเอชไอวีชาวไทยที่มีชีวิตยืนยาว กระบวนการนี้เป็น “กระบวนการของการต่อสู้เพื่อการมีชีวิตอยู่อย่างปกติร่วมกับเชื้อเอชไอวี” เป็นกระบวนการที่ผู้ติดเชื้อจะต้องสู้เพื่อเอาชนะความทุกข์ยาก ตลอดจนปัญหาต่างๆจากการติดเชื้อ เพื่อบรรลุภาวะของการมีชีวิตอยู่อย่างปกติ กระบวนการนี้ประกอบด้วยระยะต่างๆที่ต่อเนื่องกันสี่ระยะคือ ระยะหลีกเลี่ยง ระยะลุกขึ้นสู้ ระยะสู้เพื่อการมีชีวิตอยู่ และระยะของการมีชีวิตอยู่อย่างปกติ ในระยะหลีกเลี่ยง ผู้ติดเชื้อจะหลีกเลี่ยงหรือหนีปัญหาที่เกิดจากการติดเชื้อ ระยะลุกขึ้นสู้ซึ่งเป็นระยะที่สอง เป็นช่วงเวลาที่ผู้ติดเชื้อเปลี่ยนตนเองจากการหลีกเลี่ยงปัญหา มาสู่ภาวะที่พร้อมจะสู้เพื่อการมีชีวิตอยู่ ซึ่งเป็นการเข้าสู่ระยะที่สาม ระยะสู้เพื่อการมีชีวิตอยู่เป็นระยะที่ผู้ติดเชื้อต้องพยายามดิ้นรนและทำงานอย่างหนักในการเอาชนะปัญหาความยากลำบากต่างๆ เพื่อการดำรงชีวิตและการบรรลุเป้าหมายของชีวิต ระยะสุดท้ายเป็นระยะของการมีชีวิตอยู่อย่างปกติ ผู้ติดเชื้อจะรับรู้ตนเอง และดำเนินชีวิตของตนเหมือนคนปกติทั่วไปในสังคม ผลการศึกษายังชี้ให้เห็นว่า การรับรู้ของผู้ติดเชื้อเอชไอวีหรือเอดส์เปลี่ยนแปลงตลอดเวลาจากทัศนคติในทางลบไปสู่ทัศนคติในทางบวก แต่ละระยะของกระบวนการเผชิญปัญหาได้วิเคราะห์ในรูปของเงื่อนไขเชิงสาเหตุ เงื่อนไขเชิงบริบท เงื่อนไขแทรกซ้อน กลยุทธ์ในการจัดการ และผลที่เกิดขึ้น

ทฤษฎีเชิงสาระที่ได้จากการศึกษาครั้งนี้ช่วยให้เกิดความเข้าใจกระบวนการเผชิญปัญหาของผู้ติดเชื้อเอชไอวีที่มีชีวิตยืนยาวอย่างลึกซึ้ง ความรู้นี้สามารถใช้เป็นแนวทางในการพัฒนาโปรแกรมการช่วยเหลือผู้ติดเชื้อให้มีการเผชิญปัญหาที่มีประสิทธิภาพนับตั้งแต่เริ่มแรกที่รู้ติดเชื้อ โปรแกรมการช่วยเหลือควรเป็นชุดของการกระทำที่มีความต่อเนื่องและปรับเปลี่ยนไปตามเงื่อนไขของผู้ติดเชื้อที่เปลี่ยนแปลงไป และควรมีการวิจัยเพื่อประเมินประสิทธิภาพของโปรแกรมการช่วยเหลือที่พัฒนาขึ้นต่อไป

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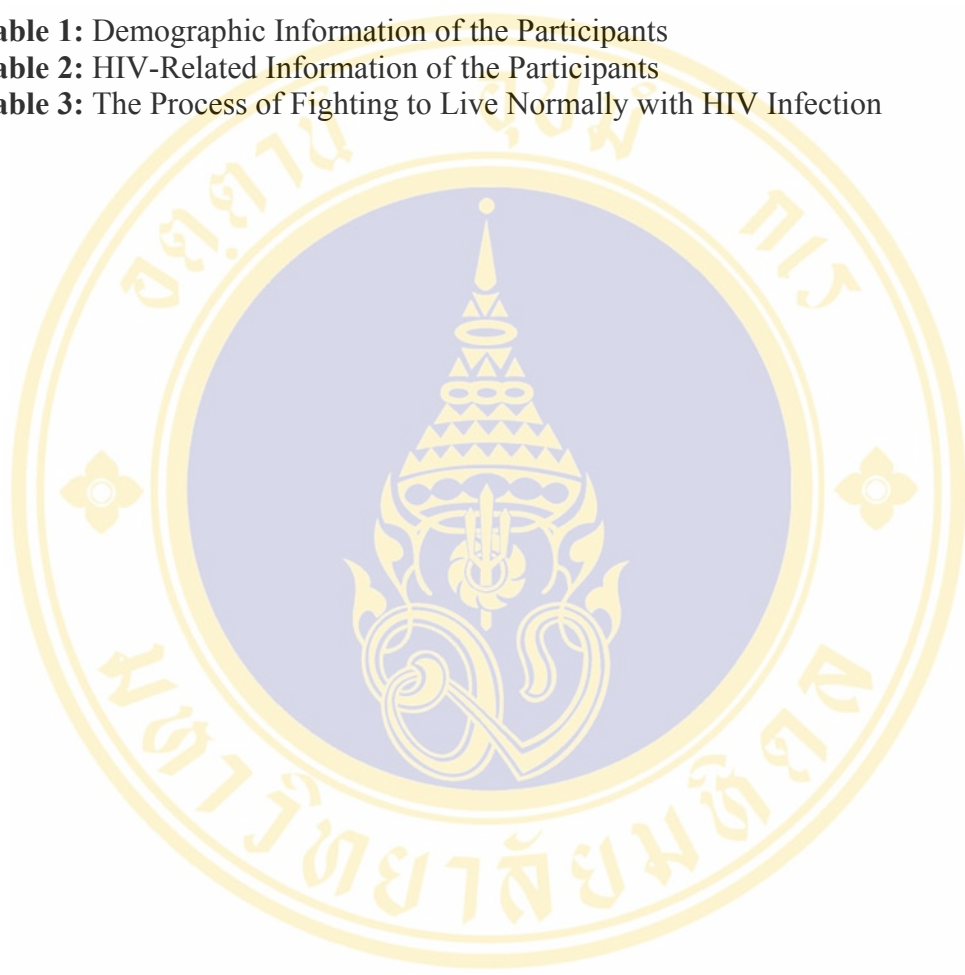
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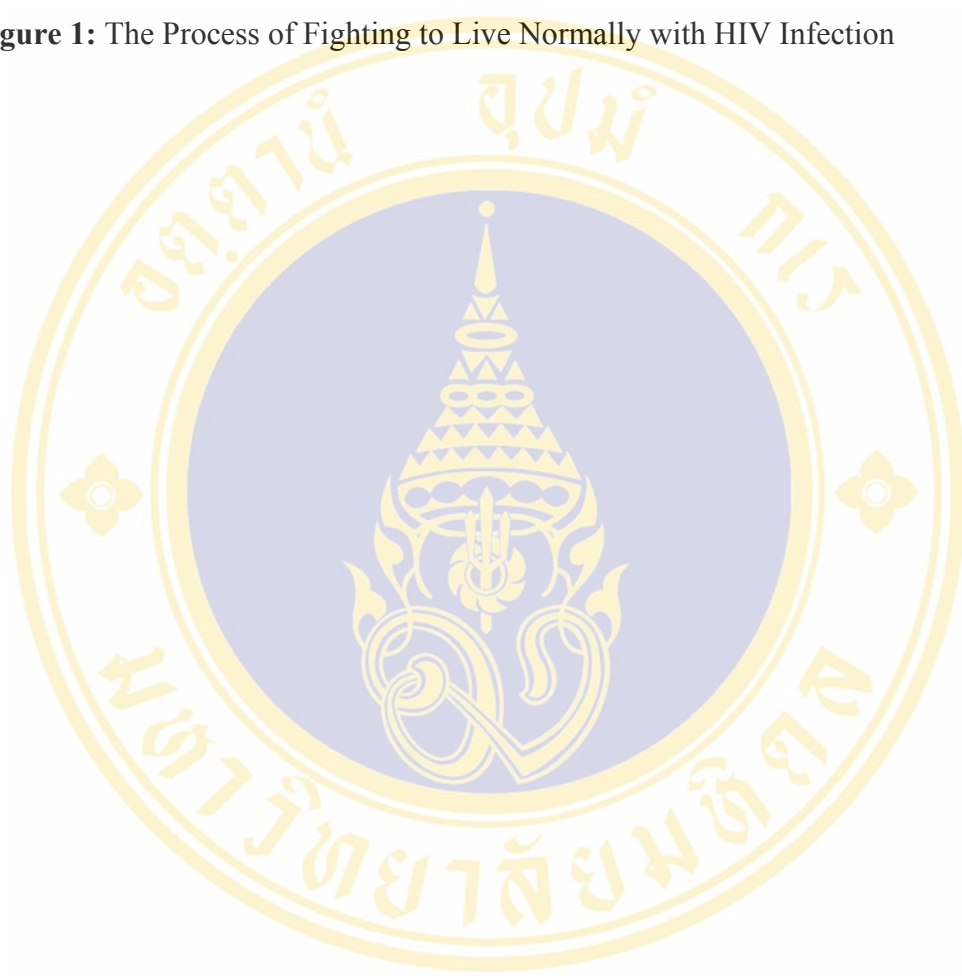
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CHAPTER I

INTRODUCTION

Background and Rationale of the Study

Acquired immunodeficiency syndrome (AIDS) has become a major social and public health problem in Thailand since the early 1980s. In 1984, a case of AIDS patient was first reported in a man who was homosexual (Limsuwan, et al. 1986: 164-169). A few years later, human immunodeficiency virus (HIV) rapidly spread among injecting drug users, female prostitutes and their clients, and then from the male clients to their wives, girlfriends, and their newborn children (Weniger, et al. 1991: 571-577). The number of HIV-infected people and AIDS patients in Thailand has rapidly and continuously increased. By the year 1997, there were approximately 750,000-800,000 HIV- infected people in Thailand and nearly 80,000 AIDS cases reported (Pooncharern, et al., 1998). Among Asian countries, the Thai population probably has the highest proportion of people infected with HIV (Mastro, et al. 1998: 49).

A review of research in social sciences (Boonmongkol, et al., 1999: 751) has indicated that the cost of treatment and care of AIDS patients, especially anti-retroviral therapy, is higher than that the Thai government can support. The epidemic of AIDS in Thailand also creates economic problems, social problems, and public health problems to the families and communities. Many children and elders are left in the families and communities because of the early death of their parents and their sons or daughters from AIDS. HIV-infected mothers also abandon their babies in the hospitals after births. The families of HIV-infected people or AIDS patients lose the opportunities to keep money and children lose the opportunities for education because of their families' economic problems. Moreover, the epidemic of tuberculosis, a by-product of AIDS, potentially becomes an important health problem of the community again.

HIV-disease progression can be classified into four patterns: average progressors, rapid progressors, long-term nonprogressors, and long-term survivors. The average progressors, accounting for 65% to 90% of HIV-infected people, become AIDS within ten years after the infection. The rapid progressors, about 3% to 10% of infected people, develop signs and symptoms of AIDS within two to three years after the infection. Approximately 5% to 8% of infected people are long-term non-progressors (LTNPs) who remain asymptomatic and maintain a CD4⁺ T cell counts above 500 cells/ μ l over a decade or more without taking any anti-retroviral medication. As for the last pattern, long-term survivors (LTSSs) are people who have been infected for more than ten years regardless of CD4⁺ T cell count and the occurrence of any signs or symptoms of HIV-related diseases and AIDS (Bachetti & Moss, 1989: 251; Buchbinder, et al., 1994: 1124-1125; Haynes, et al., 1996: 324; Pantaleo, et al., 1993: 327; Petrucci, et al., 1997: 245; Ruxrungtham, 1998b: 11). It is worth noting that some people define LTSSs as people with AIDS for 3 or more years (Barroso, 1995: 44; Rabkin, 1993: 371). However, there is no report about the percentage of the pattern of LTSSs (Ruxrungtham, 1998b: 11).

The patterns of HIV disease described above are concluded from studies in the Western cohorts. There is still no appropriate study to address the patterns of disease progression in HIV-infected Thai people in particular (Ruxrungtham, 2000: 40). A prospective study in Thai people with HIV-infection found that 25% of asymptomatic HIV-infected persons develop AIDS within two years (Sirivichayakul 1993, cited in Mutsigapantha, 1999: 119). This indicates that HIV-infected Thai people progress to AIDS faster than those in the Western countries.

In the past decade, the LTNPs and factors affecting HIV-disease progression have become the subjects of intensive investigation, since they may yield important information on the determinants of non-progression. This information is useful in developing and designing intervention strategies to contain the disease and help the HIV-infected people live longer without AIDS. Studies have suggested that multiple factors, including host factors, viral factors, and therapeutic factors, as well as complex interactions of these factors, account for HIV-disease progression rate (Ruxrungtham, 1998b: 12-18). However, the actual roles of these factors have not

been clearly understood, and the findings on several factors are somewhat contradictory.

Biomedical research has revealed that LTNPs have robust immune responses to their infection and their lymph nodes retain their structure and immune function. By contrast, those with progressive disease had eroded lymph nodes and generally poor immune responses. In addition, long-term nonprogressive people have relatively low levels of circulating viral particles as well as low levels of viral DNA and RNA (Barker, et al., 1998: 3108-3110; Buchbinder, et al., 1994: 1126; Cao, et. al. 1995: 201; Haynes, et al., 1996: 325; Lefrere, et al., 1997: 1136; Lifson, et al., 1991: 959; Pantaleo, et. al. 1995: 209, 212-213). Their strong immune responses to HIV indicate that they are continually exposed to viral antigens and attest to the continued replication of the virus over many years since their acute infection. Although nonpathogenic viral phenotype has been proposed as a factor contributing to the nonprogression of HIV-disease, this just appears to be in only some cases of LTNPs and is not supported by many studies (Barker, et al., 1998: 3105; Baltimore, 1995: 260; Cao, et al., 1995: 201; Kirchhoff, et al., 1995: 230; Mourich, et al., 1999: 1573). Moreover, anti-retroviral therapy can decrease the progression of AIDS and death in HIV-infective progressors but cannot explain the nonprogression of HIV-disease in LTNPs. Most of LTNPs have never taken anti-retroviral therapy because their CD4+ cell counts are more than the indicative level for the therapy (Buchbinder, et al., 1994: 1125-1126; Petrucci, et al., 1997: 245; Ruxrungtham, 1998a: 223). Therefore, these findings have suggested the possibility that people with long-term nonprogressive infection represent some special circumstance of the virus-host interaction (Baltimore 1995: 259). Nevertheless, clear explanation of such interaction remains to be discovered.

To be an HIV-infected person is a severely stressful life event. Individuals infected with HIV experience various negative psychosocial consequences such as depression, anxiety, uncertainty, numerous losses, low self-esteem, loneliness, alienation, social isolation, guilt associated with life-style, hopelessness, and suicidal ideation (Dilley, et al., 1985: 82; Govoni, 1988: 749-756; Holland, & Tross, 1985: 760; Marzuk, et al., 1988: 1333). Stressful life events, depression or depressive symptoms, anxiety, and interaction of life adversity and depression have been found

as factors related to the declination of immune function in HIV-infected people. The declination of immune function then might promote the disease progression (Burack, et al., 1993: 2568; Leserman, et al., 1997: 279; Patterson, et al., 1995: 299; Robinson, et al., 1999: 22-27).

The coping pattern or coping strategy to deal with stressful life events and various negative psychosocial consequences is one factor of the variable host responses to HIV-infection that is related with HIV-disease progression, and it might play some role in virus-host interaction. Fighting spirit which is composed of reframing stress to maximize personal growth, planning a course of action, and seeking social support, is related to less progression of HIV disease one year later (Leserman, 1992, cited in Mulder, 1999: 107; Solano, et al., 1993, cited in Mulder, et al., 1999: 108). The use of denial to cope with a newly learned HIV seropositive diagnosis can predict lower CD4+ cell counts one year later, and it also relates to a greater likelihood of progression to clinical AIDS two years later (Ironson, et al., 1994, cited in Mulder, 1999: 108).

Coping strategies are also related with psychological distress in HIV-infected people, which in turn affects their immune function and the course of the HIV-disease. It was found that the use of avoidance coping is associated with greater distress, mood disturbance, anxiety, and depression in HIV-infected people. In contrast, the use of active strategies has been reported to be associated with lower levels of psychological distress (Fawzy, Namir & Wolcott, 1989: 35; Fleishman & Fogel, 1994: 156; Leserman, Perkins & Evans, 1992: 1514; Namir, et al., 1987, cited in MacIntyre & Holzemer, 1997: 34; Nannis, Patterson & Semple, 1997: 13; Wolf, et al., 1991: 171).

However, there is evidence suggesting that avoidance coping is an adaptive coping style at the asymptomatic stage of HIV infection. Avoidance coping in asymptomatic HIV-infected gay men is associated with less progression of the HIV-disease over a seven-year period, whereas cognitive and behavioral coping is not related to disease progression (Mulder, et al., 1999: 110-111). Moneyham and colleagues (1998: 351) found that the use of avoidance coping decreases and active coping increases as physical symptoms increase. The results have also suggested that active coping is more likely to be used with increasing levels of physical symptoms,

and the individuals at various stages of the HIV disease may require different appropriate coping strategies. Coping of the individuals with HIV infection is therefore changed overtime as a process.

Studies concerning coping with HIV infection were mostly conducted in AIDS patients, and some were done broadly in different stages of HIV infection (Andrew, 1995: 36-43; Coward, 1994: 331-336; Gaskins & Brown, 1992: 111-121; Gloersen, et al., 1993: 44-58). Limited research specifically in LTNPs and LTSs has been carried out, however. For Thai people living with HIV/AIDS, studies on coping are limited, and the subjects also generally include all stages of HIV infection. Some of them aimed to examine the relationships among coping behavior, psychosocial adjustment, and other psychosocial variables such as social support (Kabinlapat, 1998: 9; Kusuma Na Ayuthya & Somnarin, 1997: 4; Sittichamlong, 1999: 4), and uncertainty (Katekaewmanee, 1999: 8; Sittichamlong, 1999: 4). One study aimed to test the effects of the family support program on adaptation to AIDS (Jaikaew, 1997: 8).

The findings of these studies have been presented from the perspectives of the researcher rather than from the perspectives of Thai people living with HIV/AIDS. A few literatures provide some understanding of coping strategies or coping processes from the viewpoints of these people, mostly including all stages of HIV infection. Sangchat (1999: 86-89) reviewed research on coping of Thai people with HIV/AIDS. She divided the psychosocial responses of these people into four phases: emotional crisis, psychological adjustment, behavioral adjustment, and living with AIDS. The coping strategies used in each phase were also described. In addition, Treemanka (1996: 117-122) explained the methods of coping with HIV infection among women in the northern Thailand. Wattanapailin (1996: 197-198) described the coping process and the influences of social supports on the coping process of asymptomatic HIV-positive persons who had known their HIV infection diagnosis for a period ranging from a few days to five years. Finally, Tansriratanawong (1998: 70-87) described spiritual healing in Thai Buddhist persons with HIV infection.

However, the coping process of Thai people who are LTNPs and LTSs has not been reported. How these groups of Thai people perceive and cope with HIV infection is not yet known. Studies on LTNPs and LTSs have been found in the Western cohort, mostly in biomedical research and few research studies are related to psychosocial

aspects. Some describe the personality and characteristics of LTSs with AIDS (Rabkin, et al., 1993, cited in Strawn, 1995: 32; Temoshok, 1988, cited in Nicholas & Webster, 1996: 394), some describe psychosocial strategies related to longer survival with HIV/AIDS (Ironson, et al., 1995, cited in Barroso, 1999: 243), and others describe what they have done to become LTNPs (Barroso, 1999: 242-248; Crossly, 1997: 1863-1873). These findings are presented as themes and sub-themes, but they do not delineate as the process of coping, which LTNPs and LTSs pass through. More information about coping process of these people, including Thai people is therefore needed.

Research Question

The research question of the study is “what is the coping process of persons with long-term HIV infection?”

Purpose of the Study

The purpose of the study was to generate a substantive theory that described and explained how long-term HIV-infected Thai persons, who had been HIV-infected for ten or more years, cope with their infection and the problems or events related to the infection. These people could maintain their health status or survive over 10-year period despite of the HIV infection. Their perception of HIV infection was also described. Ground theory methodology was used for this study.

Conceptual Framework of the Study

This study used Antonovsky’s Salutogenic Model and Lazarus’ Model of Stress and Coping as the conceptual frameworks for guiding the initial interview questions or areas for investigation. The following sections are the description of these two models.

Antonovsky's Salutogenic Model

Aaron Antonovsky, a professor of medical sociology, developed the Salutogenic model in 1979. The focus of the model is to explain why some people stay healthy despite severe stressful life events and how they manage to stay healthy (Antonovsky, 1979: 8-10). The model has proposed that these people have a strong sense of coherence, which is the way of seeing the world that facilitates successful coping with the innumerable, complex stressors confronting them in the course of living (Antonovsky, 1993: 725). A strong sense of coherence will enable persons to mobilize their generalized resistance resources that promote the effective coping with the stressors and tension. Then the successful tension management maintains one's place on the health ease/dis-ease continuum (Antonovsky, 1979: 183-186).

The model views health as a continuum and uses the term "health ease/dis-ease continuum" or "breakdown continuum". "Health ease" or "low breakdown" refers to the healthy end of the continuum, while "health dis-ease" or "high breakdown" refers to the opposite end of the continuum. Breakdown is conceptualized by four crucial facets: pain, functional limitation, prognostic implication (a state or condition defined by professional health authorities), and action implication (the action required to maintain one's health) (Antonovsky, 1979: 55-65).

A sense of coherence is defined as a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that 1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable; 2) the resources are available to one to meet the demands posed by these stimuli; 3) these demands are challenges, worthy of investment and engagement (Antonovsky 1987: 19). As defined, it is a generalized, long-lasting way of seeing the world and one's life in it. It is perceptual, with both cognitive and affective components. Its referent is not this or that area of life, this or that problem or situation, this or that time, or this or that stressor. It is shaped and tested, reinforced and modified not only in childhood but also throughout one's life (Antonovsky, 1979: 124-125).

The sense of coherence is composed of three core components. The first component, **comprehensibility**, refers to the extent to which one perceives the stimuli that confront one as making cognitive sense as information that is ordered, consistent, structured, and clear rather than as noise-chaotic, disordered, random accidental, and inexplicable. The second component, **manageability**, refers to the extent to which one perceives that resources are at one's disposal which are adequate to meet the demands posed by stimuli that bombard one. And the third component, **meaningfulness**, refers to the extent to which one feels that life makes sense emotionally, that at least some of the problems and demands posed by living are worth investing energy in, are worthy of commitment and engagement, are challenges that are "welcome" rather than burdens (Antonovsky, 1987: 16-19).

According to the model, an individual's sense of coherence is shaped by life experiences. The more these experiences are characterized by consistency, participation in shaping outcome and an underload-overload balance of stimuli, the more one begins to see the world as being coherent and predictable. The tentative sense of coherence is formed in childhood. It begins to be transformed into definitiveness in adolescence and into a considerable degree of permanence in early adulthood. Once one's sense of coherence is formed and set, its fluctuation will be minor (Antonovsky, 1979: 184-188).

Generalized resistance resources (GRRs) are any characteristics (physical, biochemical, artifactual-material, cognitive, emotional, valiative-attitudinal, interpersonal-relational, and macrosociocultural) of the person, the group, or the environment that can facilitate effective tension management (Antonovsky, 1979: 99-103). GRRs is a major determinant of a strong sense of coherence which provide one with sets of meaningful, coherent life experiences (Antonovsky, 1979: 122-189). The two major sources of GRRs are childbearing patterns and social-role complexes, in a given sociocultural and historical setting (Antonovsky, 1979: 184, 191).

A stressor is defined as a demand made by the internal or external environment of an organism that upsets its homeostasis, restoration of which depends on a nonautomatic and not readily available energy expending action (Antonovsky, 1979: 72). Stressors are ubiquitous in human existence. Everyone throughout life is fairly continuously exposed to the stressors (Antonovsky, 1979: 76-77). There are

physical, biochemical, and psychosocial stressors. The stressors create a state of tension, which is the response of an individual to a stressor (Antonovsky, 1979: 185, 10).

The role of the sense of coherence has three directions. First, by mobilizing GRRs at one's disposal, a strong sense of coherence can avoid one's being subjected to some stressors. Second, it allows one to define some stimuli, which others might perceive as stressors, as innocuous or even as welcome. And the third, it mobilizes GRRs to resolve the tension and overcome the stressors. Overcoming the stressors and resolving tension is in turn a life experience that reinforces the sense of coherence (Antonovsky, 1979: 193-195). A state of tension can have pathological, neutral, or salutary consequences. The outcome depends on the adequacy and efficiency of tension management. Poor tension management leads one to a state of stress, a response to the failure of managing tension and overcoming stressors, and movement toward dis-ease on the continuum. On the other hand, successful tension management pushes one toward the ease end of health continuum (Antonovsky, 1979: 10, 71).

Lazarus's Model of Stress and Coping

Richard Lazarus, a social personality psychologist, first developed the cognitive theory of stress and coping in 1966 as interaction framework (Lazarus, 1966) and it was modified in 1978 as a transaction framework (Lazarus, & Launier, 1978). In transaction model, stress is neither an environmental stimulus, a characteristic of a person, nor a response. Stress is conceptualized as a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and as endangering well-being. Transactional perspective views the person and the environment in a dynamic, mutually reciprocal, bi-directional relationship. It also implies process, since the environment is constantly changing, and so is the person and his or her relationship with it (Lazarus, & Folkman, 1984: 293-299; Lazarus, & Launier, 1978: 288-289).

The theory has identified two processes--cognitive appraisal and coping--as critical mediators of stressful person-environmental relationships and their immediate and long-term outcomes. The immediate effects are physiological changes, positive or

negative feelings, and quality of encounter outcome (Lazarus & Folkman, 1984: 305). The long-term effects are social functioning, morale or life satisfaction, and somatic health outcome (Lazarus & Folkman, 1984: 181-182).

Lazarus and Folkman (1984: 31-35) describe cognitive appraisal as a process through which the person evaluates whether a particular encounter with the environment is relevant to his or her well-being, and, if so, in what way. There are two kinds of cognitive appraisal: primary and secondary. In primary appraisal, the person evaluates whether he or she has anything at stake in this encounter. There are three kinds of primary appraisal: (1) irrelevant, (2) benign-positive, and (3) stressful.

When an encounter with the environment carries no implication for a person's well-being, it falls within the category of **irrelevant**. **Benign-positive** appraisals occur if the outcome of an encounter is construed as positive, that is, preserves or enhances well-being. These appraisals are characterized by pleasurable emotions such as joy, love, happiness, exhilaration, or peacefulness. **Stress** appraisals include harm/loss, threat, and challenge. In **harm/loss**, some damage to the person has already been sustained, as in an incapacitating injury or illness, recognition of some damage to self- or social esteem, or loss of loved or valued persons. **Threat** concerns harm or losses that have not yet taken place but are anticipated. **Challenge** appraisal has much in common with threat in that it too calls for the mobilization of coping efforts. The main difference is that challenge appraisals focus on the potential for gain or growth inherent in an encounter, and they are characterized by pleasurable emotions such as eagerness, excitement, and exhilaration, whereas threat centers on the potential harms and is characterized by negative emotions such as fear, anxiety, and anger.

Two main sets of variables jointly influencing whether the appraisal is that of threat or challenge are environmental and personality centered. Some environmental circumstances impose too great a demand on a person's resources, whereas others provide considerable skills and persistence, thereby influencing whether threat or challenge will occur. A range of personality characteristics including values, commitments, and beliefs about oneself and the world influences whether a person is more prone to threat or to challenge. The more confident to overcome dangers and obstacles a person is, the more likely the person is to be challenged rather than

threatened. On the other hand, a sense of inadequacy promotes threat (Lazarus, 2000: 202).

In secondary appraisal, the person evaluates what can be done to overcome or prevent harm or to improve the prospects for benefit. Various coping options are evaluated. Secondary appraisals of coping options and primary appraisals of what is at stake interact with each other in shaping the degree of stress and the strength and quality of the emotional reaction (Lazarus, & Folkman, 1984: 35).

Primary and secondary appraisals are continually changing because all encounters with the environment are continually changing and generating feedback about the psychological situation. Feedback about the environment, or from one's own actions and reactions, constitutes new information to be evaluated. It is the process of further evaluation called **reappraisal**. It is basically no different from other kinds of appraisal except for its coming later. The term reappraisal implies the continuous nature of a person's evaluations of transactions with the environment and emphasizes their responsiveness to feedback (Lazarus, 1991: 134).

Lazarus and Folkman (1984: 141-142) have defined coping as “constantly changing cognitive and behavioral efforts to manage (i.e., reduce, minimize, master, or tolerate) specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person.” This definition addresses coping as a process oriented as reflected in the word “constantly changing.” It also implies a distinction between coping and automatized adaptive behavior by limiting coping to demands appraised as taxing or exceeding a person's resources, so it excludes automatized behaviors and thoughts that do not require effort.

Lazarus and Folkman (1984: 150-153) have identified two major functions of coping: dealing with the problem that is causing the distress (problem-focused coping) and regulating emotion (emotion-focused coping). **Problem-focused coping** strategies encompass efforts to define the problem, generate alternative solutions, weigh the costs and benefits of various actions, take actions to change what is changeable, and, if necessary, learn new skills. Problem-focused efforts can be directed outward to alter some aspect of the environment or inward to alter self. Many of the efforts to alter self fall into the category of reappraisals, including changing the

meaning of the situation or event, reducing ego involvement, or recognizing the existence of personal resources or strengths.

Emotion-focused coping strategies are directed toward decreasing emotional distress. These tactics include such efforts as distancing, avoiding, selective attention, minimizing, positive comparison, and wresting positive value from negative events. Emotion-focused coping is the more common form of coping used when events are not changeable (Lazarus, & Folkman, 1984:150).

Lazarus and Folkman (1984: 158-159) have noted that the ways people actually cope depend heavily on the resources that are available to them and the constraints that inhibit use of these resources in the context of the specific encounter. Resources are viewed as factors that precede and influence coping, which in turn mediates stress. The primary resources are properties of the person, which include health and energy (a physical resource), positive beliefs (a psychological resource), and problem-solving and social skills (competencies). The remaining categories are more environmental and include social and material resources. Constraints are factors that restrict the ways an individual deals with the environment. These factors arise from person agendas and environment. Personal constraints refer to internalized cultural values and beliefs that prescribe certain types of action or feeling and psychological deficits that are a product of the person's unique development (Lazarus, & Folkman, 1984: 165). Environmental constraints may compete the same resources, thwart the effective use of resources, or respond to people's coping efforts in ways which negate their strategies (Lazarus, & Folkman, 1984: 166-167).

Both Antonovsky's Salutogenic Model and Lazarus' Model of Stress and Coping were used to guide this study. The Salutogenic Model which aims to explain why some people stay healthy despite severely stressful life events and how they manage to stay healthy (Antonovsky, 1979: 8-10) lead the investigator the question for this research: "How long-term HIV-infected people cope to maintain their health status or survive over a ten-year period despite of the HIV infection, which is a severely stressful life event."

Antonovsky's Salutogenic Model (Antonovsky, 1979) has proposed that "a strong sense of coherence will enable persons to mobilize their generalized resistance

resources that promote the effective coping with the stressors and tension.” A sense of coherence is the way of seeing the world and one’s life in the world. It is perceptual, with both cognitive and affective components. Thus, this model was used to guide the investigator to explore how long-term HIV-infected Thai people perceive HIV infection, themselves, and their lives after HIV infection; and how their perception affects their coping process.

Lazarus’ model has provided a conceptual clarification on coping. The model addresses coping as a process and defines it as “constantly changing cognitive and behavioral efforts to manage specific demands that are appraisal as taxing or exceeding the resources of the persons.” All encounters of persons with the environment are viewed as continually changing and generating feedback about the psychological situation. Feedback about the environment, or from one’s own actions and reactions, constitutes new information for persons to be re-evaluated, which is called “reappraisal”. The model also identifies two major functions of coping, which are dealing with the problem and regulating emotion. The ways people cope depend heavily on the resources that are available to them and the constraints that inhibit the use of these resources in the context of the specific encounter. Thus, this model was used to guide the interview questions to explore how long-term HIV-infected Thai people cope with the feelings, thought, problems, and events they have regarding their HIV-infection and what factors or conditions influence their coping.

Scope of the Study

This study aimed to explore the perception of long-term HIV-infected Thai people about HIV infection, themselves, and their lives after the infection as well as their coping process. The participants of the study were Thai people who had been infected with HIV for ten or more years. They lived in the communities and may or may not have had follow-up with physicians. Also, they may or may not have had HIV-related diseases, and may or may not have taken anti-retroviral therapy.

Definition of the Terms

Long-term HIV-infected people

Long-term HIV-infected people are defined as people who are seropositive for human immunodeficiency virus and have known their HIV-seropositivity from the serological test for ten or more years ago. They may or may not have any signs or symptoms of HIV-related diseases.

Coping process

Coping process is defined as a series of cognitive and behavioral efforts of long-term HIV-infected Thai people in dealing with their feelings, thought, problems, and events in their lives related to HIV-infection.

Significance of the Study

This research was expected to shed light on a substantive theory grounded in the long-term HIV-infected Thai people's perceptions and interpretations of their coping process with HIV infection. The theory would help nurses and health professionals understand these people's perceptions and their responses to HIV infection from their own perspectives. The theory would also inform nurses and health professionals about their coping strategies in dealing with their HIV infection and managing the problems or events in their lives related to HIV-infection as well as the conditions facilitating their coping process.

An understanding of the process of coping among long-term HIV-infected Thai people who can maintain their health for a long time or can live longer with HIV infection will guide the development of healthcare plans, strategies, and interventions to help and care HIV-infected people and AIDS patients. Nurses could apply the knowledge for counseling HIV-infected people and also provide the supportive environment or conditions to facilitate their coping process that will promote their health and wellness.

CHAPTER II

REVIEW OF THE LITERATURE

This chapter proceeds with a review of selected literature that is relevant to the current study. The literature is organized into three sections. They include 1) the natural history of HIV infection, 2) factors affecting HIV-disease progression, and 3) empirical evidence related to coping with HIV-infection. A brief review of the literature on the natural history of HIV-infection is aimed to describe the typical course of HIV-infection and the patterns of HIV-disease progression. Multiple factors including host factors (biological, psychosocial, and behavioral), viral factors, and therapeutic factors, which have been found to have some role in determining rate of HIV-disease progression, are reviewed. The empirical evidence related to coping with HIV-infection are reviewed from both Western and Thai literature. This section is presented in five subtopics: 1) stressors of persons with HIV/AIDS, 2) psychosocial responses of persons with HIV/AIDS, 3) coping with HIV/AIDS, 4) coping with HIV/AIDS among long-term nonprogressors (LTNPs) and long-term survivors (LTSS), and 5) stress and coping of Thai people with HIV/AIDS.

The Natural History of HIV-Infection

The typical course of HIV infection includes a primary infection phase, a clinical latency or asymptomatic infection phase, and then a stage of clinically apparent disease characterized by increased susceptibility to opportunistic infections with CD4⁺ T lymphocyte less than 200 cells/ μ l (Pantaleo, et al., 1993; Kantakamalakul, 1998: 87-88). The rate of disease progression in the individuals infected with HIV varies widely. Studies indicate that most of the HIV-infected people, 65 % to 90 %, are average or typical progressors. They develop AIDS within 10 years (Bacchetti & Moss, 1989: 251; Buchbinder, et al., 1994: 1125; Haynes, et al., 1996: 324; Pantaleo, et al., 1993; Raxrungham, 1998b: 11). A small percentage, approximately 3 % to 10 % of HIV-infected people named as rapid progressors,

progress to AIDS within 2 to 3 years of HIV infection (Buchbinder, et al., 1994: 1125; Fauci & Lane, 1998; Haynes, et al., 1996: 324). And the remaining, about less than 10 to 30 percent, are people who have lived with HIV infection for over 10 years (Lefrere, et al., 1997: 1135). These individuals can be classified into 2 groups-- long-term nonprogressors (LTNPs) and long-term survivors (LTSs) (Fauci & Lane, 1998).

The LTNPs represent less than 5 % to 8 % of HIV-infected people. According to the most recent valued-definition, they are defined as HIV-infected individuals who remain asymptomatic and maintain a CD4⁺ T cell count above 500 cells/ μ l over a 10-year period without taking any anti-retroviral medication (Barker, et al., 1998: 3105; Buchbinder, et al., 1994: 1124; Lefrere, et al., 1997: 1135; Petrucci, et al., 1997: 245). However, the definitions of LTNPs are somewhat arbitrary. Most LTNPs studies conducted to date have used different criteria to include all HIV-infected persons showing nonprogression or slow progression to AIDS. The definitions are found to be different in the time period of nonprogression ranging from over 6 to over 10 years, and the quantity of CD4⁺ T cells, ranging from greater than 400 to greater than 600 cells/ μ L and some consider the CD4 slope equal or more than zero. Nevertheless, most definitions include the absence of anti-retroviral therapy (Cohen, Kinter, & Fauci, 1997: 36-37; Lifson, et al., 1991: 959; Petrucci, et al., 1997: 245; Sheppard, et al., 1993: 1159). The LTSs are the individuals who have lived with HIV-infection for over ten years regardless of CD4⁺ T-cell count and the occurrence of any signs or symptoms of HIV-related diseases and AIDS (Fauci & Lane, 1998). Some people define LTSs as people who have lived with AIDS for three or more years (Barroso, 1995:44; Rabkin, et al., 1993: 371).

The pattern of HIV-disease progression described above has been concluded from studies in Western cohorts. There is still no appropriate study to address the patterns of disease progression in HIV-infected Thai people (Ruxroongtham, 2000: 40). Most studies of HIV-infected Thai people are cross-sectional and retrospective designs. The time of seroconversion of the people is mostly unknown. One prospective study in Thai people with HIV-infection found that 25 % of asymptomatic HIV-infected persons develop AIDS within 2 years (Sirivichayakul, 1993, cited in Mutsigapantha, 1999: 119). This indicates that HIV-infected Thai people progress to AIDS faster than the Western cohorts do. It may be due to the low socioeconomic

status of HIV-infected Thai people who have improper hygiene, higher rate of intercurrent illnesses, and delayed seeking healthcare (Ruxrungtham, 2000: 40).

The studies on people with long-term HIV infection mostly focus on LTNPs but are rarely found in LTSs. The LTNPs have become the subject of intensive investigation for a decade because they may yield important information on the determinants of non-progression that may be useful in designing new intervention strategies to contain the disease.

Factors Affecting HIV-Disease Progression

The natural history of HIV infection demonstrates the broad range in HIV-disease progression rates. This highly variable rate of progression may be the result of complex interactions between multiple factors, including the variable host responses to the infection, viral factors, and therapeutic factors.

Host factors

Host factors play an important role in determining rates of disease progression in HIV-infected individuals. Host factors include biological factors, psychosocial factors, and behavioral factors.

1. Biological host factors

Biological host factors include genetic factors and immune responses. With regard to genetic factors, it has been demonstrated that LTNPs have some types of major histocompatibility complex (MHC) class I and class II genes that might promote a salutary immune responses to HIV. The actual role of these genetic backgrounds in determining the HIV disease progression has not been clearly understood (Haynes, et al., 1996: 326; Ruxrungtham, 1998b: 14). Less than 50% of LTNPs were found to have genetic defect of CC chemokine receptor 5 (CCR5), which is a major co-receptor for macrophage (M)-tropic strain of HIV-1. Thus, HIV-infected CCR5 wild-type individuals may arrive at the same non-progressor by other mechanism (Cohen, Kinter, & Fauci, 1997: 37-38).

Immunologically, LTNP have vigorous immune responses to HIV. They have high levels of CD8⁺ T lymphocyte especially in the first year after seroconversion and high levels of antibodies that do not fall over time (Cao, et al., 1995: 201; Haynes, et al., 1996: 325; Lifson, et al., 1991: 959; Pantaleo, et al., 1995: 209; Petrucci, et al., 1997: 244). CD4⁺ T cell also appears to be quite stable over time or have lower declination rate compared with the progressors (Buchbinder, et al., 1994: 1125-1126). In addition, their lymph nodes retain their structure and immune function (Pantaleo, et al., 1995: 212). By contrast, those with progressive disease had eroded lymph nodes and generally poor immune responses (Cohen, Kinter, & Fauci, 1997: 38-41; Pantaleo, et al., 1995: 209, 212; Ubol & Dhitithanyanont, 1998: 53-65). Although the host immune responses to HIV-infection are more clearly understood, the role and the mechanisms of immune cells and their soluble factors suppression of HIV replication in LTNP remain to be established (Cohen, Kinter, & Fauci, 1997: 40-41; Haynes, 1996: 327; Ubol & Dhitithanyanont, 1998: 51, 56).

2. Psychosocial factors

A number of studies have suggested that psychosocial variables, such as personality and attitudes, psychological distress, coping strategies, and social support/social network, may be associated with HIV disease progression.

2.1 Personalities and Attitudes

Rabkin, et al. (1993: 371) described a group of LTSs who were gay men with AIDS-defining opportunistic infection at least three years. Nearly all participants displayed an extraordinary psychological resiliency in the face of adversity. Some of the essential characteristics of these LTSs were the ability to reframe one's view of situations to keep a positive attitude, a realistic acknowledgement of life's challenges, and the ability to maintain goals and active life. The investigators also observed that men with more limited physical functions were less optimistic about the future.

Temoshok (1988, cited in Nicholas & Webster, 1996: 394) conducted a longitudinal psychosocial study of men with AIDS and AIDS-related complex. The investigator indicated that longer-term survivors with HIV scored significantly higher on the control subscale of Kobasa's hardiness instrument than did those individuals who succumbed to AIDS. Thus, it was concluded that control component of hardiness

personality is the tendency to believe and act in a way that influences life's events rather than feeling helpless when they confront with adversity (Kobasa, 1979: 3).

Ironson, et al. (1995, cited in Barroso, 1999: 243) integrated bodies of literature that examined psychological characteristics related to disease progression in HIV/AIDS. They identified psychosocial strategies related to longer survival with HIV/AIDS. Two of these strategies were having a sense of meaning or purpose in life and maintaining perspective.

According to the perception of LTNP, an important factor accounting for their good outcomes is a positive attitude. This involves staying in control, minimizing HIV and death, not worrying, and viewing HIV as a manageable illness (Barroso, 1999: 242-249; Crossley, 1997: 1863-1873; Troop, et al., 1997, cited in Barroso, 1999: 243).

Finally, Reed, et al. (1994: 299) identified a pattern of response to AIDS termed realistic acceptance in a study of men with AIDS. They defined realistic acceptance as a fundamentally cognitive response related to negative disease-specific expectations in the context of AIDS. They found that the mean estimated survival time for participants with high scores on realistic acceptance was 9 months shorter than for participants with low realistic acceptance scores. They further investigated whether the negative HIV-specific expectancies, AIDS-related bereavement, and their interaction could predict the onset of HIV-related symptoms among asymptomatic HIV-positive gay men (Reed, et al., 1999: 354-363). The subjects had been HIV-positive for approximately 3 years (ranging from 2.5 to 3.9 years) and they were followed for an additional 2.5 to 3.5 years with symptom status assessed every 6 months. The investigators found that only the interaction of negative HIV-specific expectancies and bereavement was a significant predictor of symptom onset. Negative HIV-specific expectancies predicted the subsequent development of symptoms among bereaved men after controlling for immunological status, use of anti-retroviral drug, high-risk sexual behavior, substance use, and depression.

2.2 Psychological distress

HIV-seropositive individuals often report higher levels of psychological distress including depression and anxiety than seronegative individuals (Antoni, et al., 1991 cited in Robinson, Mathews, & Witek-Janusek 1999: 24). The

field of psychoneuroimmunology (PNI) is attempting to describe and measure the impact of these psychological distresses on immune function and HIV disease progression. Although these relationships are not yet understood, there is evidence to believe that such relationships exist. In a meta-analysis of studies on depression and immunity, Herbert and Cohen (1993, cited in Strawn, 1995: 32-33) concluded that clinical depression is reliably associated with decreases in all measures of lymphocyte function. McCain and Zeller (1996: 39) reviewed 36 PNI studies in HIV/AIDS and concluded that there is general support for relationships between stress/coping patterns and clinical symptoms as well as immune measures in HIV-infected persons. However, PNI studies in HIV/AIDS have yielded some contrary results.

A few prospective studies aimed to examine the relationships among depression, immune function and disease progression in HIV-seropositive men without AIDS. For instance, Burack, et al. (1993: 2568) found that depression could predict a more rapid decline in CD4 counts, but there was no association between depression and earlier AIDS diagnosis or earlier mortality in the period of 66-month follow-up. Furthermore, Lyketsos, Hoover, & Gurcione (1993: 2563) conducted an eight-year prospective study and found that depressed men had lower CD4 counts and reported more AIDS-related symptoms. However, the declination of CD4 in depressed subjects did not significantly differ from non-depressed subjects. Moreover, the proportion of AIDS diagnoses or death was not different between depressed and non-depressed men. Lastly, Leserman, et al. (1997: 279) reported that severe stress (stressful life events), and depressive symptoms were independently related to decreases on immune measures from entry to 2-year follow up, that is, declines in CD8⁺ T cells, and natural killer cell subsets. Subjects most likely to have decreases on these immune measures were those who scored above the median on both stress and depressive symptoms. These finding still cannot conclude that depressive symptoms independently prognosticate AIDS or death in HIV-infection, but they suggest that depressive symptoms may have clinical implication for the course of HIV disease.

Patterson, et al. (1995: 299) used multiple regression method to test whether psychosocial variables could predict HIV-associated decline in health. A set of nine psychosocial measures and interactions was used as the independent variables. Biological markers of HIV disease progression, including absolute number and

percentage of CD4 cells and serum β_2 -microglobulin, were dependent variables. The set of 9 independent variables accounted for 30% of the variance in percentage change of CD4 cells over 6 months. The most significant predictor of the change in percentage of CD4 cells was the interaction of life adversity and depression. This interaction variable was also the significant predictor of increase in β_2 -microglobulin. Thus, in this study, the variables that predicted the disease progression were not single variables, but they were the combination of psychosocial variables (depression and life adversity).

Some studies found no relationships between psychological distress and immune parameters or immunosuppression. For example, Ironson, et al. (1990: 247) found that psychological distress or anxiety levels, measured at the time of notification for gay men found to be HIV positive, were not related to lymphocyte proliferation. There was a relationship between increased anxiety and decreased natural killer cell cytotoxicity, measured one week later. Rabkin, et al. (1991: 111) reported that HIV-positive homosexual men, who were depressed or anxious or who reported more life stressors at baseline, had no significantly lower CD4 cell counts than did others, either concurrently or during a 6-month interval. No significant correlation was also detected between any of the measures of psychiatric distress and stage of HIV illness. Perry, et al. (1992: 396) found similar results in socio-demographically-heterogeneous adults with HIV-infection. The result showed no significant concurrent correlation among CD4 counts and any of the psychological variables, including depression, anxiety, and psychiatric symptoms. Similarly, no significant prospective relationships were found between psychological measures at baseline and subsequent CD4 cell counts one year later. The failure to demonstrate the relationships between psychological distress and immune function might be due to the interval between measurements that was either too short or too long to show significance (Rabkin, et al. 1991; Robinson, et al., 1999: 27). Another cause might be the problem of CD4 cell count, which may not be a sensitive indicator of depression/distress-induced immune changes (Robinson, et al., 1999: 24; 27).

A number of studies investigated the influence of psychological factors on immune processes relevant to HIV disease progression via the release of cortisol, produced during stress. Robinson, et al. (1999: 22-24) have recently reviewed the

studies on this issue. The review showed that two psychiatric states of depression and anxiety have significantly positive relationships to 24-hour urinary-free cortisol levels. Increases in plasma cortisol levels have been associated with decreases in circulating lymphocytes. Cortisol also has an inhibitory action on natural killer cell activity. It also inhibits the production of T-helper cell 1 (Th1) cytokines and enhances T-helper cell 2 (Th2) cytokine production. A predominant Th1 cytokine profile with its dominant cellular immune response is more protective against HIV disease progression than is a dominant Th2 profile. Th1 cytokines are secreted by immune cells and coordinate the healthy immune responses. In addition, cortisol can increase the ability of HIV to infect lymphocytes and increase the expression of HIV by mononuclear cells. Therefore, it is plausible that elevated levels of cortisol associated with psychological distress may accelerate the course of illness by encouraging a predominant Th2 as opposed to Th1 cytokine response pattern. This condition may promote the replication and infectibility of HIV and then lead to HIV disease progression.

2.3 Coping strategies

Few studies have examined the influence of coping strategies on the course of HIV-related diseases, and they have yielded contradictory results. Griensven, et al. (1990, cited in Mulder, et al. 1999: 111) found no associations between coping and the development of markers for progression of HIV infection over the follow-up period of approximately 3 years. Eich-Hochli and colleagues (1997: 479-480) reported similar results that coping strategies are not correlated with the progression of HIV disease at 1 or 2 years later.

Solano, et al. (1993, cited in Mulder, et al. 1999: 108) found that having a fighting spirit is related to less progression of HIV disease 1 year later. Fighting spirit is an adaptive coping, which is composed of reframing stress to maximize personal growth, plan a course of action, and seek social support (Leserman, 1992, cited in Mulder, 1999: 107). Ironson and colleagues (1994, cited in Mulder, 1999:108) found that the use of denial to cope with a newly learned HIV seropositive diagnosis predicted lower CD4 cell counts 1 year later and a greater likelihood of progression to clinical AIDS 2 years later. These results are in contrast

with the findings of a study by Mulder, et al. (1999: 110-111). Mulder and colleagues found that avoidance coping in asymptomatic HIV-infected gay men was associated with less decline in CD4 cells, less appearance of syncytium-inducing (SI) variants, and less progression to immunologically defined AIDS (CD4<200 cells/ μ L) over a 7-year period. On the contrary, cognitive and behavioral coping, which is similar to fighting spirit, was not related to the declination of CD4 cells, the appearance of syncytium-inducing variants, and the progression to AIDS. It should be noted that these studies did not use the same biomedical outcome measures.

2.4 Social support and social network

The studies on the relationships between social support and disease progression have revealed controversy. Theorell and colleagues (1995: 32) investigated the relationship between social support and immune status reflected by CD4 counts in 49 HIV-infected men with moderately severe or severe hemophilia. Social network and social support was measured by the availability of attachment (AVAT) index. The subjects were divided into two groups: one with high AVAT and one with low AVAT scores. The result indicated that a low AVAT score was associated with a significantly more rapid progressive deterioration in CD4 count during subsequent five years. Other studies found that social support was significantly correlated with health status in HIV-positive persons (Nicholas, & Webster, 1993: 132; Nunes, et al., 1995: 174) and AIDS patients (Temoshok, 1987, cited in Strawn, 1995: 31). Receiving support from others and giving to others are also perceived by LTNPs as important factors in maintaining their good health and longer survival (Barroso, 1999: 246-247; Ironson, et al., 1995, cited in Barroso, 1999: 243).

However, some studies did not found the relationships between social support, or social network, and immune status, health status, or disease progression in HIV-positive persons. Nicholas and Webster (1996: 402) found no relationship between social support and CD4 cell counts or social support and health status in various stages of HIV-positive individuals. Furthermore, Eich-Höchli and colleagues (1997: 476-484) prospectively evaluated the relationships between psychosocial variables and the development of clinical symptoms over a period of 2 years in 89 asymptomatic HIV-infected people. Social network as one psychosocial variable was not related to symptom development or disease progression at 1 or 2 years later. In

this study, social network measure examined an individual's perception of his or her social network, i.e. the number of good or bad relationships, as well as the importance and quality of emotional and practical aspects of social support.

3. Behavioral factors

Lifestyle and personal actions were important determinants of a good prognosis with HIV-infection (Troop, et al., 1997: 133). Important behavioral factors are taking care of physical and mental health or self-care activities. Taking care of physical and emotional/mental health were mentioned by LTNPs and LTSs with AIDS as ways for maintaining their health (Barroso, 1995: 44-53; Barroso, 1999: 246-247). A healthy diet; decreasing alcohol, recreational drugs, and smoking; personalized medication regimen such as vitamins, herbs, and taking prescription medications in dosages other than those recommended by health care provider; and adequate rest and exercise were mentioned by most of the informants for taking care of their physical health. On the other hand, taking care of emotional/mental health encompass both behavioral and cognitive strategies such as decreasing stress, staying busy, doing enjoyable things, doing meditation, etc.

These self-care activities in taking care of one's physical and mental health, perceived by both LTNPs and LTSs with AIDS as an important component to maintain their health or reconstruct their lives, have been supported by several studies. MacIntyre and Holzemer (1997:25-38) reviewed the literature on complementary and alternative medicine and HIV/AIDS. There was evidence that asymptomatic HIV-positive men, who had received a program of complementary therapies, had a 4% decrease in CD4 counts over the intervention period, whereas the comparison group (did not receive the program) had an 18% and 49% decrease in CD4 counts. The program included nutrition counseling, vitamin and herbal supplementation, stress reduction, exercise, and community involvement for 30 months.

MacIntyre and Holzemer (1997: 26-29) also reviewed literature on nutrition and HIV/AIDS. Studies on nutritional status and HIV disease progression revealed that inadequate nutrition decrease total T-lymphocytes as well as helper and suppressor cells, resulting in increased susceptibility to opportunistic infections. Decreases in nutritional markers such as body mass index, serum albumin, and transferrin are predictive of hospitalization and death. Vitamins A deficiency in HIV-

positive people has been associated with increased disease progression and mortality. A decrease in beta-carotene has been associated with altered neuropsychiatry function, impaired interleukin-2 production and impaired lymphocyte proliferation.

Exercise training is also an important component of good health in individuals who are HIV-infected. LaPerriere and colleagues (1997: s56-s61) reviewed the effects of exercise training on the enumeration of CD4 cells in HIV/AIDS. All the available literature on exercise training in HIV/AIDS revealed no decline in CD4 cell counts, regardless of the initial stage of disease, level of CD4 cells, or symptomatology. Moreover, there was a trend toward an increase in the number of CD4 cells for some. The largest increases in CD4 cells had been reported in those individuals at the early stages of the disease. It appears that the earlier in the disease spectrum and the less immunocompromised an HIV-infected individual is, the more of an increase in CD4 cells is seen following exercise training. Thus, they suggested that exercise training might play a role in management of psychological stress that has been implicated among the cofactors contributing to the immunological decline in HIV disease.

These reviews have shown that self-care activities especially on nutritional status and exercise have some account on the good outcomes of HIV-infected individuals who are LTNPs or LTSs.

Viral factors

Virological studies showed that HIV can not be detected in plasma of LTNPs, or can be detected in only few cases of them (Barker, et al., 1998: 3108-3109; Buchbinder, et al., 1994: 1126; Cao, et al., 1995: 201). Low levels of viral particles, such as HIV-RNA, have been detected in plasma, peripheral blood mononuclear cells, as well as lymph node mononuclear cells of LTNPs. Viral particles in plasma continually increase over time in a low rate. Thus, viral replication persists over time but generally less well than progressors (Barker, et al., 1998: 3108; Lefrere, et al., 1997: 1136; pantaleo, et al., 1995: 212-213). This low level of HIV-RNA has been proposed as a strong predictor of HIV disease progression and clinical outcome (Mellors, et al., 1996: 1167; O'Brien, et al., 1996: 105). Viral phenotype might be

another factor associated with HIV disease progression. However, this just appears to be in only some cases and others studies failed to demonstrate this relationship (Barker, et al., 1998: 3105; Baltimore, 1995: 260; Cao, et al., 1995: 201; Kirchhoff, et al., 1995: 230; Mourich, et al., 1999: 1573).

Therapeutic factors

Early studies (Fischl, et al., 1987: 185; Volberding, et al., 1990: 941) found that Zidovudine (AZT) given to people with AIDS or AIDS-related complex, and asymptomatic HIV-infected people with CD4⁺ cell counts less than 500 cells/ μ L significantly decreased the opportunistic infections and death rates compared with the placebo-control group. When compared the effects of immediate therapy and deferred therapy with AZT in asymptomatic HIV-infected people with CD4⁺ cell counts over 500 cells/ μ L, no different effects on disease progression and death rates between two groups were found. Subjects in the deferred therapy group received AZT when their CD4⁺ cell count was less than 500 cells/ μ L (Volberding, et al., 1990: 941). From this result, the level of CD4⁺ cell counts less than 500 cells/ μ L in HIV-infected individuals has been an acceptable indicator for anti-retroviral therapy (Ruxrungtham, 1998a: 223).

Nowadays, combination therapy or multi-drug regimens have been demonstrated to obtain the full benefit of therapy. Combination therapy exhibits more efficacious than mono-therapy or single-drug therapy in the control of HIV disease progression through viral suppression and maintaining or increasing CD4⁺ cell counts (Ruxrungtham, 1998a: 223-238; Ruxrungtham, 1998b: 18).

Anti-retroviral therapy with combination of multi-drugs appears significantly in decreasing the progression of AIDS and death in HIV-infective progressors, but it cannot explain the absence of disease progression in LTNPs. These people have CD4⁺ cell counts more than 500 cells/ μ L, and therefore most of them have never taken any anti-retroviral therapy (Buchbinder, et al., 1994: 1125-1126; Petrucci, et al., 1997: 245). In addition, few LTNPs (less than 3%) believed that medical treatments such as anti-retroviral drugs were the reasons of their good outcome with HIV. However,

most of LTNPs believed that a positive outlook, lifestyle, and personal action are important determinants of their good prognosis (Troop, et al., 1997: 133).

Empirical Evidence Related to Coping with HIV-infection

The literature on coping with HIV infection is reviewed and presented in 5 sections. They are 1) stressors of persons with HIV/AIDS, 2) psychosocial responses of persons with HIV/AIDS, 3) coping with HIV/AIDS, 4) coping with HIV/AIDS among LTNPs and LTSs, and 5) stress and coping of Thai people with HIV/AIDS.

Stressors of persons with HIV/AIDS

The potential stressors or causes of distress among persons living with HIV infection are numerous. These stressors reported in a large number of literatures were described from the experiences of both HIV-positive individuals and healthcare providers or counselors who work with these individuals. The stressors can be classified into psychosocial and physiological stressors. Psychosocial stressors include stigma of HIV, multiple losses, uncertainty or lack of knowing, changes in relationships with others, economic hardship, and grief or illness of others. Common physiological stressors include fatigue, physical pain, infection, gastrointestinal complaints, respiratory complaints, sleep deprivation, night sweat, fever, itching, and weight loss.

Psychosocial stressors

1. Stigma of HIV

The diagnosis of HIV disease carries with it the image of an early death sentence and contamination. The image of finality, termination, and death can lead to a fear of the process of dying or death, and a fear that needful others such as children, spouses, older parents will be left behind. The stigma of contamination can lead to personal feelings of guilt and fear of contamination to others. Childbearing women fear of passing the disease to their children. Sexually active persons must deal with the possibility of passing the disease to others through intimacy (Andrews, 1995:

39; Coward, 1994: 333-334; Dilley, et al., 1985: 84; Sontag, 1988 cited in Andrews, 1995: 39).

In addition, HIV-positive individuals must face the stigma associated with lifestyles of high-risk groups. They all suffer from the prejudicial assumption that they must have been infected through deviant or illicit acts (Dilley, et al., 1985: 84; Korniewicz, O' Brien, & Larson, 1990: 14; Nichols, 1985: 765; Ross, 1996: 235). The phenomenology study of Bennett (1990: 146) on stigmatization experiences of persons with AIDS found that they all experienced rejection at least one as a result of having AIDS. Sources of rejection included families, partners, friends, roommates, employers, colleagues, strangers, and society in general (Bennett, 1990 cited in Korniewicz, O'Brien, & Larson, 1990: 14-15). Thus, persons with AIDS may hide the diagnosis due to fear of family crisis, social stigma, and social abandonment (Ross, 1996: 235; Wolcott, 1986 cited in Korniewicz, O' Brien, & Larson, 1990: 15). As a result of these images of HIV disease, HIV-infected persons respond psychologically to their diagnosis with feelings of guilt, fear, low self-esteem, sadness, and depression. They must deal with a burden of secrecy, including secrecy from family, friends, and colleagues to avoid being stigmatized (Coward, 1994: 333; Ross, 1996: 235). Moreover, social stigma may influence the increased suicide rate for AIDS patients (Glass, 1988: 1369-1370; Marzuk, 1988: 1333).

2. Multiple losses

Persons with HIV/AIDS face multiple losses. Physically, they lose their health, physical abilities or functioning, and cognitive ability (Dilley, et al., 1985: 236; Marshall cited in Ross, 1996: 236; Miller, 1991: 41). HIV-positive individuals may be anxious about losses of future physical functioning, particularly loss of cognitive capacity, and have a fear of becoming demented or dependent on others for basic physical cares (Marshall, cited in Ross, 1996: 236). Psychologically, they lose their body image (Ross, 1996: 236). Interpersonally, they may lose their connections and relationships with others due to rejection from their families and friends, and abandonment from their partners (Coward, 1994: 333; Dilley, et al., 1985: 84; Korniewicz, O'Brien, & Larson, 1990: 14-15). Another painful loss for some people is their loss of independence because of physical problem, medical treatment, or mental deterioration (Laschinger & Fothegill-Bourbonnais, 1999: 62;

Wolcott, 1986, cited in Korniewicz, O'Brien, & Larson, 1990: 14). Socially, persons with AIDS experience loss of social acceptance (Bennett, 1990: 142). The loss of social acceptance leads to many losses, such as career, social network, income, and even one's home. These social losses affect their ability to function socially. In addition, some HIV-infected women reported loss or fear of loss of social roles, such as mother, wife, and sexual partner (Chung & Magraw, 1992, cited in Strawn, 1995: 32).

3. Uncertainty/Lack of knowing

The most pervasive feelings voiced by AIDS patients are anxiety, fear, and anger over the uncertainty surrounding their illness and treatment (Dilley, et al., 1985: 84; Marshall, cited in Ross, 1996: 236). Women with AIDS reported that they experienced several forms of uncertainty. They could not predict the behavior of others related to their diagnosis, the periods of their illness or wellness, and how long they would be able to continue their mission (Coward, 1994: 334). Laschinger and Fothergill-Bourbonnais (1999:62-63) studied the experience of pain in persons with HIV/AIDS, and one of the theme that emerged was "the pain of not knowing." What was painful for most of the participants in the study was 'not knowing where their physical pain was coming from,' and 'whether it had to do with HIV disease, their medications, or a simple illness.' The specific information about the course of their illness, received from their physicians, did not always progress as predicted. As a result, the participants noted that they found it difficult to make future plans in their lives.

4. Economic hardship

Thompson, Nanni, and Levine (1996: 9) assessed the stressors of people with HIV and found that financial problems were the most frequently reported. Some of these people had a decrease in income, a burden of medical costs, and a loss of housing, which was rated as the most stressful event (Bloom, & Carliner, 1988: 604; Thompson, Nanni & Levine, 1996: 9).

5. Changes or problems in relationships with others

Persons with HIV/AIDS had mentioned changes that they experienced in their relationship with others when they disclosed their HIV status (Laschinger & Fothergill-Bourbonnais, 1999: 63). In general, they have difficulty forming and

maintaining relationship with others. Fear that disclosing HIV status will lead to a rejection from others may prevent relationships forming, while fear of transmitting HIV infection to an uninfected sexual partner may curtail the intimacy of a relationship (Marshall, cited in Ross, 1996: 236). Some HIV-positive people reported problems with healthcare providers and some problems with their co-workers (Thompson, Nanni & Levine, 1996: 9).

6. Grief/illness of others

Grief is a human response to an experience of the death of a loved one such as spouse, lover, or close friends. During the grieving, persons often feel a sense of being isolated from others (Mallinson, 1999a: 164). Loss of a loved one will leave the survivor feeling sad, angry, fearful, lonely, and empty (Mallinson, 1999b: 24). Death of closed friends, family members, and spouse or lovers have also been reported as stressors of some HIV-positive persons. The illness of these significant persons including stress of their caregivers has been reported as stressors of these individuals as well (Thompson, Nanni & Levine, 1996:9).

Thompson, Nanni, and Levine (1996:5) assessed stressors and rated stress in HIV-positive men. The investigators found that these subjects experienced high numbers of stressors and elevated levels of perceived stress and depression. Stressors in the areas of relationships and finances were the most problematic and were associated with more depression.

Physiological stressors

Longo, Spross, and Loche (1990: 25) identified major physical concerns of persons with AIDS. Thirty-four subjects were interviewed using semi-structured questions. The data showed that 41% and 44% of subjects described fatigue and weight loss, respectively, as major concerns. Moreover, Survellén, Sarna, and Jabonski (1998: 445) described women's experience with HIV symptoms. They interviewed 44 convenient women and revealed that the majority of these women (78%) stated only one symptom as most bothersome. Fatigue (e.g., "feeling tired," "hard to (can't) get up") was the most frequently reported worst symptom, followed by symptoms associated with infection (e.g., candidiasis and herpes). Other symptoms mentioned by the participants were headache, pain (e.g., neuropathies and muscular aches), gastrointestinal complaints (e.g., diarrhea, nausea, and vomiting), respiratory

and sinus complaints (e.g., cough, shortness of breath, allergies, and congestion), night sweats, negative mood, and itching.

A phenomenology study was recently conducted by Laschinger and Fothergell-Bourbonnais (1999: 61-62) to understand the experience of pain in 22 individuals with HIV/AIDS. The phenomenon of pain appeared to be interpreted by the participants in a broad manner. The four themes that emerged from the data were physical pain, painful losses, the pain of not knowing, and social pain. For the physical pain, participants frequently complained of joint pain, headache, neuropathic pain, abdominal pain, painful skin lesions, and mouth pain (including painful teeth and gums). The type of pain was dependent on the disease process that was secondary to HIV infection. Headaches and abdominal pain were two frequent pain problems associated with taking the medication used to treat HIV disease.

For all of these stressors (problems), distressing emotions, relationship difficulties and HIV-related symptoms were reported as the three most frequently experienced problems (88%, 75%, and 74%, respectively) and the three problems of most concern (31%, 33%, and 30%, respectively) by 96 HIV-infected gay men (Pakenham, Dadds, & Terry, 1996: 245-249). Furthermore, there was a trend for instrumental difficulties such as physical symptoms, employment, financial, treatment, etc. to increase with disease progression, whereas emotional and existential problems, such as distressing emotions, depression, grief/bereavement, did not vary as a function of HIV stage (Pakenham, Dadds, and Terry, 1996: 248-249).

Psychosocial responses of persons with HIV/AIDS

Nichols (1985: 765-766), with his personal experiences in caring for several hundred of AIDS patients, described the psychological reactions of persons with AIDS in three phases: crisis, transitional state, and deficiency or acceptance state. An initial crisis is an acute response of denial. The usual emotional reactions in this phase include shock, denial, guilt, fear, anger, sadness, bargaining, and acceptance. The second, the transitional state, begins when altering waves of anger, guilt, self-pity, and anxiety supersede denial. This period is a time of distress, confusion, and disruptiveness. Social rejections are deeply felt, aggravating the situation. Changes in

self-esteem, identity, and values, estrangement from families and community, and consideration of suicide may also occur. Loss of job, income, and one's home may be additional stressors in this phase. Consequently, fear and depression, rather than anger, is more likely to be exhibited by the patients. In the third, the deficiency or acceptance state, patients form a new, stable identity. They learn to accept the limitation that AIDS imposes on them but also realize that they can still manage their lives by reacting to the disease with more reason than emotion. They subsequently feel less victimized by life, become less egocentric, and can find satisfaction in altruistic and community activities. They take more responsibility for their own health, sometimes experimenting with holistic medical practices such as positive imaging, macrobiotic diets, and meditation.

Ross, Tebble, and Viliunas (1989, cited in Ross 1996: 235-236) identified seven stages of psychosocial responses to HIV infection in homosexual men. These stages of response include 1) shock with, guilt, powerlessness, anger, and denial; 2) withdrawal with the processes of recognition of stigma and isolation; 3) "coming out" to significant others for testing their reactions with the need of love; 4) looking for other HIV-positive people for sharing, recognition, trust, positive reinforcement, and social support; 5) special status with the processes of turning alienation into a unique advantage, becoming special and needed by others; 6) altruistic behavior with the processes of group commitment and cohesiveness, giving and sharing, and feeling of community; and 7) acceptance by integrating HIV-positive status with self-identify, and balancing between altruism and self. Ross (1996: 235) noted that not all patients go through all these stages.

Gaskins and Brown (1992: 113-115) specifically investigated initial psychosocial responses in 10 gay and bisexual men with HIV. Men in this study reported shock, anger, and fear of the future when they were told the diagnosis. Their initial responses to the diagnosis included facing the reality of death, deciding whom to tell, and changing lifestyles.

Lastly, McGuckin (1996: 237) described emotional and psychological responses to symptomatic HIV disease. The responses can be as varied as the symptoms themselves. The responses may be greatest with the onset of a particular symptom, especially if this symptom can potentially cause substantial disability and

dependence (such as loss of sight or memory). There may also be a “crisis” associated with the symptoms and sequelae of the first AIDS-related illness, particularly if this results in hospitalization. The responses can include fear, anxiety, and uncertainty about a range of issues (pain, dependence, prognosis, death and dying), as well as depressive symptoms and thoughts of suicide.

Coping with HIV/AIDS

The correlational studies investigated the relationships between coping strategies and HIV-disease progression have been described earlier in the topic of factors affecting HIV-disease progression. Other studies investigated the relationships between coping strategies and psychological distress and quality of life. According to a number of research results, avoidance from problems has been assumed to be a passive and ineffective coping strategy, whereas cognitive and behavioral coping has been assumed as an active or adaptive coping strategy. It was found that HIV-positive homosexual men who reported greater use of avoidance coping also reported greater distress than those who used more active coping strategies (Fawzy, Namir & Wolcott, 1989: 35). Avoiding coping was also related to greater total mood disturbance, anxiety, and depression. In contrast, the use of active strategies has been reported to be associated with lower levels of psychological distress (Fleishman & Fogel, 1994: 156; Leserman, Perkins & Evans, 1992: 1514; Namir, et al., 1987, cited in MacIntyre & Holzemer, 1997: 34; Nannis, patterson & Semple, 1997: 13; Wolf, et al., 1991: 171).

The findings of Mulder and colleagues (1999: 110-111) appear inconsistent with these findings. They found that avoidance coping in asymptomatic HIV-infected gay men was associated with less progression of HIV diseases, whereas cognitive and behavioral coping was not related to disease progression. Although they did not investigate the psychological outcomes, their finding suggested that avoidance coping was an adaptive coping style at the asymptomatic stage of HIV-infection. Mulder and colleagues proposed that avoidance coping style such as trying to avoid difficult situations, trying to withdraw from them, focus on other things, and reconciling

oneself to the facts are appropriate ways to handle this inescapable life threatening infection.

Mulder and colleagues' suggestion was supported by Rose and Clark-Alexander (1996: 31-32) who found that passive and emotional-focused coping styles were positively related to total score of quality of life (QOL), but confrontive coping style was not related to QOL in asymptomatic HIV-positive women with children. In addition, Moneyham and colleagues (1998: 351) found that current avoidance coping was not related to emotional distress. They reported that the use of avoidance coping decreased and active coping increased as physical symptoms increased. This study suggested that active coping is more likely to be used with increasing levels of physical symptoms. Finally, an experimental research in HIV-positive men with advanced HIV-disease was conducted to test the effects of an intervention based on developing cognitive coping skills as compared to one focused on facilitating the expression of emotions. The results indicated a decrease in distress and anxiety for the cognitive group, whereas no change in distress and an increase in anxiety were found in the emotion-expression group (Côté' & Pepler, 2002: 237-241). These results suggest that individuals at various stage of HIV-infection may require different appropriate coping strategies.

For the naturalistic studies, Barroso and Powell-Cope (2000: 340-350) did a metasynthesis of 21 articles of qualitative research on the experience of adults living with HIV infection. They found the following themes: finding meaning in HIV/AIDS, shattered meaning, human connectedness, focusing on the self, negotiating healthcare, and dealing with stigma. Finding meaning in HIV/AIDS was an introspection about life and the self, led to new strategies for living, and resulted in the assimilation of HIV/AIDS into one's life. Shattered meaning was the opposite of finding meaning. HIV was viewed as irreparable and massive loss, and led to overwhelming fear. Human connectedness involved initiating and sustaining meaningful relationships with friends and family members in the face of increasing alienation and separation from others. Focusing on the self was defined as a set of actions that participants took to enhance both their physical and emotional health. Negotiating health care was defined as efforts to assume an active role in care. Dealing with stigma involved dealing with reactions to HIV infection on personal, familial, and societal levels.

Allan (1990: 56-60) described the self-care activities used by HIV-seropositive, asymptomatic gay men with a range of one to 36 months of known HIV-seropositivity. One aspect of the study was on coping and help seeking. The informants of the study did a few manageable actions that, they believed, would keep them healthy and prevent them from getting AIDS. They developed personal regimens that involved a process of experimenting, seeking information from professional and alternative care sectors, and consulting with partners and friends. The most frequently mentioned actions were changes in dietary patterns and various transformations in attitudes toward life, such as focusing on living, not dying, or establishing priorities for living. In addition, most of the informants increased their exercise, tried to reduce stress by altering their job activities, or meditating, altered their life style, and altered existing relationships.

Gloersen and colleagues (1993: 45-52) identified the experiences of 16 people with AIDS who viewed themselves as doing well. The concept of “doing well” was defined as those processes by which a person with AIDS accepted it, developed a set of positive beliefs about the illness or ability to affect the illness, and engaged in various actions to achieve a general sense of well-being by conceptualizing AIDS as a manageable chronic illness or an opportunity for self-actualization. The participants of this study used seven processes to develop a sense of well-being, consisting of accepting, being active, masterful living, relating mind and body, being positive (dealing with negative and positive thinking), participating in healthcare, and experiencing support (support from others and self support). These processes assisted these AIDS patients to manage AIDS as a chronic illness or to achieve self-actualization.

Katz (1996: 52-59) explored the experiences and consequences of uncertainty in the lives after HIV diagnosis of ten persons with asymptomatic HIV infection who had never been diagnosed with an AIDS-defining illness. Thematic analysis resulted in a description of a phenomenon called “gaining a new perspective.” All participants in this study perceived their lives and the world they lived in from a new perspective. Living with HIV was described as the impetus to begin looking at themselves with clarity. They indicated personal growth as a result of having HIV disease. They maintained this new perspective through five core experiences including surviving the

HIV diagnosis, taking care, living in the present, seeking support, and appreciating the positive. Each core experience was supported by a number of actions.

Laschinger and Fothergill-Bourbonnais (1999: 59-60) studied the experience of pain in 22 persons with HIV/AIDS who had self-identified as experiencing pain since their diagnosis. The phenomenon of pain, interpreted by the participants, appeared in a broad manner. The four themes that emerged from the data were physical pain, painful losses, the pain of not knowing, and social pain. Three categories of coping strategies used to deal with pain were identified. First, pharmacological and complementary therapies included massage, meditation, special diets, relaxation exercise, yoga, acupuncture, and transcutaneous electric nerve stimulation. Second, strategies drawing on internal resources were mentioned by all of the participants. They needed to be part of the decision-making process surrounding their situations through reading and gaining information from the expertise of professionals. Some participants identified the importance of having a positive attitude and the need to set and strive for goals. By striving for goals and keeping active on a daily basis, these participants perceived that they were living longer. Third, strategies drawing on interaction with one's environment, the participants used resources in their own environment to help them deal with pain. The majority of participants used the resources at the HIV clinics (healthcare personnel and materials). Some received various support forms from AIDS community. In addition, the majority of them found that giving support to others was a tangible way for them to deal with pain (Laschinger & Fothergill-Bourbonnais, 1999: 63-64).

Finally, Mellors and colleagues (2001: 235-246) described how patients with AIDS transcend the emotional and physical suffering of their illness. The findings identified three main themes: creating a meaningful life pattern, connectedness, and self-care. The first theme "creating a meaningful life pattern" includes the concepts of life transforming, personal development, and life satisfaction. The second theme "connectedness" reflects a significant, shared meaningful personal relationship that one has with another person, a spiritual being, nature, or one's inner self, involving both receiving and giving support. The last theme "self-care" includes the concepts of therapy, survival, and wellness.

Coping with HIV/AIDS among LTNP and LTSs

There are few studies of coping with HIV/AIDS in LTNP and LTSs. For example, Ironson and colleagues (1995, cited in Barroso, 1999: 243) integrated bodies of literature and identified four psychosocial strategies related to longer survival with HIV/AIDS. These strategies are healthy self-care, maintaining connectedness, having a sense of meaning or purpose in life, and maintaining perspective.

Crossley (1997: 1863-1873) conducted a study with 38 people who had been living with HIV for an average of nine years without AIDS related conditions. The researcher described that these people were committed to living positively with HIV and to empowering oneself. They did this in very different ways which could be organized into two major types: interpersonally oriented and intrapersonally/intrapersonally oriented. Interpersonally oriented individuals viewed the people around them, friends, lovers, family members, support networks, and member of society more generally to be extremely important in accounting for the fact that they lived so far in a “healthy” state. These individuals took care of themselves by carrying on life as usual or as being HIV-negative, thinking positive, minimizing the negative effects of HIV infection on their everyday, practical activities as much as possible, becoming involved in HIV related activities, and focusing on the “pleasure-seeking” side of life. On the other hand, intrapersonally/intrapersonally oriented individuals viewed HIV infection as only represented a peripheral or external problem. Their continuing health and survival could ultimately be attributed to psychic machinations such as “inner self progression” and “inner development.”

Finally, a naturalistic study (Barroso, 1999: 242-248) aimed to describe the perception of LTNP of their HIV disease and its course. The participants were HIV positive without AIDS for seven or more years and had CD4 count over 500 cells/ μ L. Twenty-five participants were asked with a question “What have you done to become a LTNP with HIV-disease?” Five themes with ways of adapting in each theme emerged from the data.

The first theme, cited by the majority of the group, was “taking care of my physical health.” Ways of adapting included healthy diet (80%); decreasing alcohol, recreational drugs, and smoking (79%); personalized medication regimen (72%);

adequate rest and exercise (68%); proper medical attention (52%); educating themselves about HIV (32%); avoidance of reinfection (28%); listen to their bodies (12%); and control over their environment (12%).

The second was “viewing HIV as a manageable illness”. Ways of adapting included compartmentalizing HIV (68%), maintaining a positive attitudes (68%), continuing to plan for future (56%), having daily structure (40%), living one day at a time (28%), maintaining identity (28%), and living in harmony with HIV (24%).

The third was “human connectedness,” which was defined as initiating and sustaining meaningful relationships with others. It includes coping with the loss of some relationships; reconstructing old ties; reaffirming positive ties with family, friends, and lovers; and constructing new social networks. It manifested itself in two ways: supportive relationships and altruism. More than a half of the informants perceived that their friends (56%) and their family (52%) were important in assisting them to maintain their health. Some mentioned developing relationships with other HIV-positive people (28%), partner support (24%), therapist or counselor support (20%), and AIDS service organization support (12%). Several participants felt that altruism was also an important factor. It included helping other HIV-positive people (40%), telling their stories to help others (20%), and protecting others from infection (20%).

The fourth was “taking care of my emotional/mental health.” This theme encompassed both behavioral and cognitive strategies. Behavioral strategies included decreasing stress (48%), staying busy doing things they enjoy (40%), and refusal to hide despite the stigma (12%). Cognitive strategies included meditation (32%), relaxation tapes (4%), and mental imaging (4%).

The last theme was “spirituality,” which manifested the two levels of beliefs. One was a belief in a supportive, protective higher power, while the other was surrender to a higher power. For the participants who believed in a higher power, they mentioned the power of prayer (32%) and noted that their higher power was a source of strength and help (24%). For those who had surrendered to a higher power, they not only mentioned the same sentiments as the above, but also discussed their belief that their higher power had a plan for their lives (20%). Some stated that they put

themselves and their HIV infection into their higher power's hands (12%), and two people (8%) felt that their higher power gave them the will to live.

Stress and Coping of Thai People with HIV/AIDS

The literature on stress and coping of Thai people with HIV/AIDS is reviewed and presented in four sections. They are 1) social construction of HIV/AIDS in Thailand, 2) perception of HIV/AIDS, 3) stressors and psychosocial responses of Thai people living with HIV/AIDS, and 4) coping of Thai people living with HIV/AIDS.

Social construction of HIV/AIDS in Thailand

The dissemination of HIV/AIDS education and prevention through mass media to warn Thai people about the danger of the disease since 1990 has provoked pervasive fear of the disease and distributed negative meanings of HIV/AIDS to Thai people. In the warning message from the mass media, HIV/AIDS is also seen as associated with “deviant” behaviors such as homosexuality, promiscuity, and drug abuse, and therefore is viewed as indicating a blemish-character. Moreover, it is seen as highly contagious and threatening to the general public (Charusab, 1997: 344-352; Lyttleton, 1996: 363).

Charusab (1997: 343-354) studied articles and news on AIDS from one of Thai newspapers between 1984 and 1993. She indicated that the press has constructed the social and cultural meanings of AIDS in fourteen categories as following. 1) AIDS is an incurable disease and death only. 2) AIDS is an awful disease. 3) AIDS is a highly contagious disease. 4) AIDS is a severe and life threatening disease. 5) AIDS is a disease of painfulness, hopelessness, and suffering. 6) AIDS is a disease of disgrace and losses. 7) AIDS is a disease everybody can catch. 8) AIDS is a disease of deviant population. 9) AIDS is a disease of sinfulness or immorality. 10) AIDS is a disease of the unfortunate. 11) AIDS is a disease of foreigner. 12) AIDS is a disease of unhealthy person. 13) AIDS is a polluted disease. 14) AIDS is a stigmatized disease. Over the past ten years, the meanings of AIDS in some categories have changed in a positive direction. The meaning in number 11 to 14 have significantly changed, number 8 to 10 have moderately changed, whereas number 1 to 7 have only slightly changed.

Perception of HIV/AIDS

The social and cultural images and meanings of HIV/AIDS greatly affect how Thai people perceive and respond to the disease and to the persons with HIV/AIDS. In a qualitative study, HIV-infected Thai people perceived AIDS as a sexual transmission disease including homosexual. AIDS was also viewed as an incurable disease and meant death only. Ones who had AIDS were unfortunate and should not disclose their status because it was not acceptable in Thai society (Chaiphibalsarisdi, et al. 1991: 13).

Songwathana and Manderson (1998: s155) conducted an ethnographic study in Southern Thailand. The data, derived from 400 women and men in villages and urban areas and from 23 people with HIV/AIDS and their caregivers, revealed that AIDS was seen as a disease without cure and a disease of promiscuity. It was also viewed as a disease of karma, as well as a disease related to dirt, danger, and death. AIDS was depicted by several pictures of patients who were very thin and pale, had ulcer and thrush in their mouth, and had ugly skin lesions covered with discharge. Participants responded to AIDS patients with great fear and anxiety. Patients with AIDS perceived that death was the only choice left for them once they were infected. Death from AIDS was seen as bad death rather than good death because it occurred after prolonged suffering and disfigurement, and most often the early deaths of young people.

Stressors and psychosocial responses

At first being informed of HIV seropositive, HIV-infected Thai people have great fear of the disease and symptoms, fear of death, and fear of being ugly. They are afraid of their HIV status disclosure because of fear of family and social rejection, as well as fear of being abandoned (Mooktharakosa, 1995: (3); Prohmpakdee, 1994: 130-132; Tansriratanawong, 1998: 100). Moreover, they have fear of passing the disease to their spouses or partners, fear of the uncertainty of their lives, and fear of losses of jobs and income (Jantanaluk, 1998: 58; Prohmpakdee, 1994: 139-141). Some HIV-infected people encounter with abandonment from their father, mother, family, and colleagues (Chaiphibalsarisdi, et al., 1991: 29-31), and nearly a half of people (44.7%) with HIV/AIDS in one study reported that the disease mostly affected their jobs and income (Samitakasetrin, 1999: 74-75).

Prohmpakdee (1994: 123-159) conducted a longitudinal qualitative study in ten heterosexual men with HIV from 1990 to 1992. He described that the informants had to face with a lot of physical and psychological problems with engagement a stage of AIDS diagnosis. Their HIV status was disclosed because of the appearance of AIDS symptoms. They had to encounter social reactions resulted from fear of and disgust at AIDS. They experienced neglect of care from healthcare providers, and adverse verbal and nonverbal expression from others. They also had distress from physical symptom such as fever, chronic cough, weight loss, diarrhea, chronic lesions, and herpes. A descriptive study to examine the levels of symptom distress and the levels of social dependency among 77 persons with HIV/AIDS (Kutchamach, 1997: 88-91) indicated that the subjects perceived high level of distress in shortness of breath, skin itching, and skin lesion. Fatigue was perceived as a moderate level of distress. As the disease progressed, the subjects' perceptions of the amount of symptom distress and the distress level were increased. Moreover, symptom distress was positively correlated with social dependency ($r = 0.58$, $p < .001$).

A number of qualitative studies described the psychological responses of HIV-infected Thai people since they had known the diagnosis (Chaiphibalsarisdi, et al., 1991: 18-31; Pradabmook, 1994: 40-45; Prohmpakdee, 1994: 129). When at first informed of HIV-infection, most of them were frightened, sad, greatly fearful, uncertain, excited, anxious, and hateful of themselves. Some people had a pale face and sat silently for a while. Some people fainted, and others denied the diagnosis. They felt unfortunate and as if they were punished. Five to 15 minutes later, they started asking about the pathology of the disease and how to live with HIV. They also looked for more knowledge and information about contamination of HIV, as well as symptoms and severity of the disease from health care personnel. Although they look calm down, most of them are in confusion, with anxiety, and are worried about their lives and their families. They also have insomnia and lose appetite. Some people isolate themselves and do not talk to anyone. The psychological status of these people would be somewhat better in one to two weeks depending upon their perception to what they encounter with, the condition of living with others, their expected goal and

commitment, and responsibilities to their families. They adjust themselves and select their own lifestyles. However, some people who could not adjust, might harm themselves or might be severely aggressive. Some people, who are abandoned and face with adverse reaction from their families and others may lose their self-confidence and isolate themselves.

Tongchom (1990, 146-152) studied the response process to HIV infection of intravenous drug users. She reported that the intravenous heroin users were not critically anxious as other HIV-infected people were. This might be the result of more experiences about crisis condition they had more than other people. The intravenous heroin users responded to HIV infection in three patterns. First, passive denial pattern was characterized by changing heroin using behaviors and decreasing HIV spreading behaviors. Their behavioral adjustment was facilitated by social support and environmental conditions. Their HIV infection was disclosed only to the persons whom they trusted. Intravenous drug users who responded in this pattern are of middle age and had used heroin to reduce work tension for many years. Second, active denial pattern was characterized by searching for the reasons to change perceptions about HIV but they did not change HIV spreading behaviors. Intravenous drug users who responded in this pattern were in troubled conditions from disclosing their HIV infection and lacked social support. They were of young age and had used heroin because of family problems or inferiority complexes. Third, the anxiety pattern was characterized by protecting self anxiously. Intravenous drug users tried to change heroin-using behaviors, decreased HIV spreading behaviors, and experienced difficulty in living in the community. These responses appeared when they were ill and identified illness linked with AIDS.

The assessment of anxiety and depression of 150 Thai people with HIV/AIDS (Samitakasetrin, 1999: 73-75) showed that anxiety was present in 26%, depression in 51.33%, and suicidal ideation in 33.3% of the sample. The subjects who had poor family-care, problems in their job/income, and problems in family and neighbor relationships had significantly more anxiety and depression than those who did not. In addition, the subjects who had been infected for six or more years had significantly more depression than those infected for less than six years. However,

there was no difference in anxiety levels among the subjects with different duration of being HIV infected.

Coping of Thai people living with HIV/AIDS

Sangchat (1998: 86-89) reviewed research on coping with HIV/AIDS and suggested that psychosocial responses of Thai people with HIV/AIDS could be divided into four phases. She also analyzed coping strategies these people used in each phase.

The emotional crisis phase: This is an initial phase after knowing the diagnosis of HIV infection. HIV-infected people response differently. They are frightened, in denial, confused, anxious, angry, sad, depressed, and afraid of losing of jobs. They were fear of death and feel as if they had lost everything in their lives. Most of them decide to conceal their HIV status. They still can't adjust their emotions and thoughts.

The psychological adjustment phase: HIV-infected people try to relieve their psychological distress. These people look for strategies or reason or meaning of life to adjust their emotions and thoughts. Some people can accept the HIV infection. Some people try to avoid discussing the disease or thinking of situations related to AIDS, and others distract themselves from AIDS by staying busy doing things, drinking, or smoking. Some people deny the diagnosis of HIV infection. They think the diagnosis is not true, and they are still normal and healthy.

Behavioral adjustment phase: This phase depends on the way the people adjust their emotions and thoughts in the former stage. People who use avoidance coping style will adjust their behaviors to conceal their HIV status, while people who accept the HIV infection will mostly adjust their behaviors to solve problems. There are many ways of coping with HIV infection in this phase. Concealing HIV status is often found among these individuals. They maintain their social roles and relationships with others as usual. Disclosure of the HIV status will happen in the needful situation or inescapable situations such as the needs of support from family and physical symptom appearances. People who accept their HIV-status have positive thinking in confronting the problems. They distract their attention to other things and relieve stress by staying busy, listening to music, and doing meditation. Performing a range of behaviors to take care of their physical health is another way of coping.

These behaviors include having healthy diet, having adequate rest and exercise, decreasing or stopping high-risk behaviors, avoiding re-infection, monitoring and instantly treating physical symptoms, and seeking healthcare from both professional and traditional medicine. Some people change their life styles such as changing jobs, careers, or residences, and some people create hope and new meaning for lives.

The phase of living with AIDS: This is the phase of progressive HIV diseases and chronic illness. People with AIDS in this phase need help, social support, and care from their families. Therefore, they disclose their HIV status to whom they confide in and need for emotional support and other resources. Their illness is also the cause of social isolation, as well as the problems of jobs and finance. Some people attempt suicide to escape from the distress.

Tansriratanawong (1998: 100-101) found that HIV-infected people who were Buddhist mostly (92.5%) reflected on their Buddhist faith and used Buddhist teachings (Dharma) as ways of coping with their illness and empowering them to find meaning in life. They practiced ten strategies: rituals (97.5%), relaxation/meditation (70%), performing prayers (47.5%), creating new meaning to find new goals of life (40%), exchanging feelings with spiritual counselors (27.5%), helping others (17.5%), increasing sense of self-worth (12.5%), reflecting on dynamic process of life cycle (12.5%), instilling hope (7.5%), and sacrifice (7.5%). The Dharma, which they used to guide their spiritual healing, prescribes refraining from evil, doing good things, and purifying the mind.

A study of coping with HIV in women living in Northern Thailand (Treemanka, 1996: 117-122) showed that these women, as a result of having encountered many hardships in their past, had individual capabilities to face with HIV infection with hope and resolve. They had normal lives with their husband and families without chronic depression, anxiety or grief, and remained emotionally balanced despite periodic mood swing. Their methods of coping with HIV infection included 1) constant seeking of new information on HIV/AIDS from many sources, 2) acceptance of their HIV status, resulting in readiness to face future problems and reduction in the severity of their situation, 3) viewing their situation in a positive way and being able to talk about their situation with people who understood them, and 4) toleration of their condition.

Wattanapailin (1996: 197-198) studied the coping process and the influences of social supports on the coping process of 32 asymptomatic HIV-positive persons who had known their HIV infection diagnosis for a period ranging from a few days to five years. The study reported that after the participants knew their HIV-seropositive status, they assessed the HIV impacts on their well-being. The assessment process varied according to the causes of HIV infection, the situations leading them to the serological test, their education, and their previous experiences with HIV. Their assessment affected the degree of stress and their normal life patterns. As stress occurred, they used various coping strategies such as denial, acceptance, redefining the HIV infection, temporary diversion of interests from HIV, caring of oneself, creating hope, and isolating from society. In addition, social support had influences on the coping process through the extent of assessment and the coping strategies of these women.

The correlational studies have investigated the relationships among coping behavior, psychosocial adjustment and other psychosocial variables. The results revealed that social support was positively related to psychosocial adjustment among HIV infected pregnant women ($r = .44$, $p < .01$) (Sittichamlong, 1999: 63-64) and to coping behavior of AIDS patients ($r = .29$, $p < .001$) (Kusuma Na Ayuthya & Somnarin, 1997: 4). Social support accounted for 32.59% of the variance of problem-focused coping behaviors in mothers with HIV-seropositive (Kabinlapat, 1998: 97-98). Family members and the acceptance of the community were found to be crucial factors involving coping ability and behavioral adaptation of people living with HIV/AIDS (Phavady, 1996: 60-61). Family support program was developed and its effects were tested on adaptation to AIDS of HIV seropositive persons through a quasi-experimental design (Jaikaew, 1997: 121-125). The results indicated that adaptation to AIDS of the experimental group was significantly higher than that of the control group. Problem-focused coping of the experimental group was also significantly higher than that of the control group, while emotion-focused coping within both experimental and control groups was not significantly different.

As for another variable, the uncertainty in illness was not related to psychosocial adjustment (Sittichamlong, 1999: 63-64) or total coping behaviors, yet it was significantly positively correlated with avoidance coping behaviors ($r = .41$, $p <$

.001) in pregnant women with HIV seropositive (Katekaewmanee, 1999: 79-80). In addition, the difference in sex, marital status, education, and family income showed significant difference in coping behaviors of AIDS patients (Kusuma Na Ayuthya & Somnarin, 1997: 4). Furthermore, the educational level was significantly positively related to coping behavior of people living with HIV/AIDS (Phavady, 1996: 60-61; Rugstipaya, 1994: 93-94). Finally, the younger people living with HIV/AIDS were found to adopt and accept their condition better than the older (Phavady, 1996: 60-61).

Summary

The rate of disease progression in the individuals infected with HIV varies widely. There are four patterns of HIV disease progression: rapid progressors, average or typical progressors, long-term non-progressors (LTNPs), and long-term survivors (LTSs). LTNPs and LTSs are individuals who have lived with HIV longer than usual. LTNPs can remain asymptomatic and maintain CD4 level, while LTSs may have symptoms and the declination of CD4 level. However, some people define LTS as people with AIDS for three or more years.

The highly variable rate of progression is believed to be the result of complex interactions between multiple factors, including the variable host responses to the infection, viral factors, and therapeutic factors. Host factors, which include biological factors (genetics and immune responses), psychosocial factors (i.e., personalities and attitudes, psychological distress, coping strategies, and social support/social network), and behavioral factors, are proposed to play important roles in determining rates of disease progression in HIV-infected individuals. The actual roles of these factors have not been clearly understood. The research findings on several factors such as genetics, psychological distress, coping strategies, social support, and viral phenotype are somewhat contradictory. LTNPs and LTSs consistently perceive some factors such as positive attitudes, social support, and self-care activities as contributing factors to their nonprogression of HIV disease.

The research on stress and coping of people living with HIV/AIDS has revealed that the psychosocial and physical stressors, which make them distress, are

numerous. Psychosocial stressors include stigma of HIV, multiple losses, uncertainty or lack of knowing, changes in relationships with others, economic hardship, and grief or illness of others. Common physical stressors include fatigue, physical pain, infection, gastrointestinal complaints, respiratory complaints, sleep deprivation, night sweat, fever, itching, and weight loss. The psychological responses of these people are continually changed over time from an initial crisis or shock, when they first learn of the diagnosis of HIV seropositive status, through the acceptance stage. However, HIV-infected individuals respond differently. Not all of these people go through the same stages or can reach the acceptance stage.

Studies related to coping with HIV/AIDS, both correlational and naturalistic studies, are reviewed. According to a number of correlational studies investigating the relationships between coping strategies and psychological distress, avoidance from problems has been regarded to be passive and ineffective coping strategy, whereas cognitive and behavioral coping has been assumed as an active or adaptive coping strategy. However, some evidence has suggested that avoidance coping is an adaptive coping style at the asymptomatic stage of HIV-infection, and the individuals at various stages of HIV-infection may require different appropriate coping strategies. For the naturalistic approach, the studies on the experiences of living with HIV/AIDS have revealed some similar core experiences such as having a positive attitude, seeking social support and giving support to others, and participating in health care.

In Thailand, social and cultural images and meanings of HIV/AIDS greatly affect how Thai people perceive and respond to the disease and to the persons with HIV/AIDS. HIV/AIDS is viewed as an incurable disease, a disease of death, promiscuity, and dirt. Thai people respond to AIDS patients with great fear and anxiety. Death from AIDS is seen as bad death rather than good death because it occurs after prolonged suffering and disfigurement, and most often the untimely deaths of young people. Thai people with HIV/AIDS also have numerous stressors. They have great fear of the disease, symptoms, death, being ugly, family and social rejection, and being abandoned. Thus, they respond to HIV/AIDS with great fear, anxiety, and depression. The ways they respond to HIV infection or how critical their responses are seem to be related to their past experiences, social support, and their conditions or problems such as family care, family problems, relationships with

neighbors, problems in their jobs and income, and difficulties in living in the community.

However, studies on coping of Thai people living with HIV/AIDS are limited. The available literature indicates that most of the HIV-infected Thai people hide their HIV status and disclose it only when necessary. These people use many and different ways of coping with HIV infection, such as acceptance, avoidance, distraction, denial, positively confronting the problems, seeking information and support, taking care of health, and changing life styles. Buddhist teachings are also frequently mentioned by these people as ways of coping with their illness and empowering them to find meaning in life.

Few studies of coping with HIV/AIDS in LTNPs and LTSs are found only in the Western cohort. These studies were naturalistic studies, which described psychosocial strategies related to longer survival with HIV/AIDS. They described what the patients had done to become LTNPs. The findings were presented as themes and categories of sub-themes. They did not delineate as the process of coping which the LTNPs passed through. Thai LTNPs and LTSs have not yet been subjects for an investigation in the area of stress and coping. Therefore, it is still unknown how these groups of Thai people experience their coping with HIV/AIDS.

CHAPTER III

METHODOLOGY

This study aimed to explore and describe the coping process of long-term HIV infected Thai people by using grounded theory methodology. This chapter describes the grounded theory, participants, setting, instrumentation, the process of data collection, data analysis, protection of human subjects, and establishment of trustworthiness.

Grounded Theory

The grounded theory approach was originally developed by two sociologists: Glaser and Strauss in the early 1960s (Glaser & Strauss, 1967). Its development was influenced by the philosophy of American Pragmatism and the sociological tradition in Chicago Sociology at the University of Chicago from the 1920s through the mid-1950s. The American Pragmatism emphasized on action and the problematic situation, and the necessity for conceiving of method in the context of problem solving. The tradition of sociology at that period of time extensively utilized field observations and intensive interviews as data collecting techniques. Both the philosophy and the tradition assumed that change was a constant feature of social life. They emphasized on social interaction, social process, and the necessity to grasp the actors' viewpoints for understanding interaction, process, and social change (Strauss, 1987: 5-6).

Stern, et al. (1982, cited in Hutchinson, 1986: 112) noted that the symbolic interactionist's perspective is the foundation for grounded theory. According to Blumer (1969, cited in Chenitz & Swanson, 1986: 5), symbolic interaction rests on three basic premises.

First, human beings act toward things on the basis of the meanings that the things have for them. These things may be objects, other human beings, institutions, guiding ideals, activities of others and situations, or a combination of these.

Second, the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows.

And third, these meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he or she encounters.

According to these premises, nothing in the world, that is, objects, people, or events, has intrinsic meaning or inherent value in and of itself. Meaning is created by the individual through interaction with the object and with self. Once the object is defined, meaning can be attached to it. The meaning the object has to the individual gives it a value (Chenitz, & Swanson, 1986: 5). Therefore, the action or behavior toward the object is based on the meaning and value it has to the individual (Blumer, 1969, cited in Chenitz, & Swanson, 1986: 5).

Chenitz and Swanson (1986: 6-7) described the implications of the symbolic interactionism for grounded theory research. The researcher needs to understand behavior as the participants understand it, learn about their world, and learn their interpretation of self in the interactions. Human behavior is studied from both the symbolic and interaction levels. It must be observed in context because meaning is derived from social interaction.

Grounded theory is a research method that aims to generate inductively based theoretical explanations of human behaviors and social and psychological processes (Baker, Wuest, & Stern, 1992: 1357). It emphasizes on developing an explanatory theory that is grounded in empirical data and derives from the actors' perspectives. The grounded theory approach is particularly appropriate for studying in the areas in which little research has been done or few adequate theories concerning a phenomenon of interests exist (Chenitz, & Swanson, 1986: 7). Since the coping process of long-term HIV-infected Thai people has not been reported, grounded theory is well suited to develop a substantive theory, derived from the participants' perspective, in explaining their coping through the social and psychological processes.

The specific methodological features of grounded theory include constant comparative method of analysis, theoretical sampling, and the use of a coding paradigm to ensure conceptual development and density (Strauss, 1987: 5). Data are generally gathered using field techniques consisting of interview and observational

methods (Stern, 1985: 150). Data collection and data analysis occur concurrently and are based on the constant comparative method. Data are coded with words that reflect the substance of what people said or the observed events, actions, or other dimensions of the phenomena. Categories are developed from the clustering of codes, and are linked to form a tentative conceptual framework. The developing theory is then expanded, densified, and verified by reduction and further data collection guided by theoretical sampling, which is the process of further data collection driven by the emerging categories and theory. Sampling continuously changes according to type of coding one is doing (open, axial, and selective coding), until all categories are saturated. This means no new or significant data emerge and categories are well developed in terms of properties and dimensions (Baker, Wuest, & Stern, 1992: 1358; Chenitz, & Swanson, 1986: 8-9; Glaser, 1978: 36; Strauss & Corbin, 1998: 25). Therefore, through this methodology, the theory, composed of the concepts (categories) and the relationships among them, are not only generated but they are also provisionally tested (Strauss, & Corbin, 1990: 24).

Participants

The participants in the present study were 20 Thai people who had lived with HIV for over ten years. They were purposively selected from the clients who attended the HIV clinics of the Bamrasnaradura Hospital and Ramathibodi Hospital, as well as from the workers and the clients of the non-governmental organizations (NGOs) working on AIDS activities. The investigator found out more cases by the introduction and recommendation from some participants, other HIV-infected persons, and the health providers who had worked with the infected people for a long time. The participants who met the following criteria were recruited for this study: (a) had been diagnosed with HIV-infection from the confirmed anti-HIV test for over ten years; (b) might or might not have physical symptoms of HIV-related disease; and (c) did not have any cognitive disorders.

Setting

The setting for this study included the Bamrasnaradura Hospital in Nonthaburi Province, the Ramathibodi Hospital in Bangkok, the offices of NGOs working on AIDS activities, and the convenient places mutually set by the participants and the investigator.

The Bamrasnaradura Hospital is well known in providing health services to HIV-infected people and AIDS patients in Thailand. The HIV clinics of the hospital provide services from 8:00 a.m. to 12:00 p.m. every workday. The majority of the HIV-infected people have health follow-ups monthly at the outpatient department of the hospital. Some HIV-infected people, who are recruited into the hospital's research projects studying the efficacy of treatments and drugs, have health follow-ups at the research center of the hospital. In addition, the HIV-infected people who had economics problems would be sent to the social welfare department of the hospital after receiving physical examinations and therapies. In this study, the interviews took place privately in a vacant examination room in the outpatient department, the counseling room in the social welfare department, or a convenient area in the research center.

The Ramathibodi Hospital is the hospital of the faculty of Medicine, Mahidol University. There are both medical school and school of nursing in the hospital. The participants were the clients of the hospital. The interviews took place in a private room or an area in the school of nursing.

The other settings were the offices of NGOs working on AIDS activities. The interviews were conducted in a private room, the garden, or a quiet corner of the offices. Another setting was a convenient place for both the participants and the investigator. The participants and the investigator mutually agreed on the place and the time for the interviews. The places for the interviews were usually in educational institutions or hospitals, which were near to the participants' home or workplace, or were familiar to the participants.

Instrumentation

The instruments used in this study included:

1. The personal and HIV-related information sheet

The personal and HIV-related information sheet (the English version is shown in Appendix A1, and the Thai version is shown in Appendix A2) consisted of biographic, socio-cultural and HIV-infection related information of the participant, such as age, sex, education, religion, marital status, occupation, incomes, number of years after HIV-infection, the occurrences of HIV-related diseases/signs and symptoms, medications (anti-retroviral therapy), and serological tests.

2. The interview guide

According to Strauss and Corbin (1990:180), the interview guides in a grounded theory study should be just as initial questions or beginning guidelines only. They may be based on concepts derived from literature or experience. These concepts provide an initial focus or a place for the investigator to start. In this study, the interview guide was based on theories of stress and coping, as well as literature related to coping with HIV infection. It was prepared by the investigator to guide the initial interview with each participant (the English version is shown in Appendix B1, and the Thai version is shown in Appendix B2). It contained open-ended questions beginning with a general statement “Tell me what has happened to you since you first knew you are infected with HIV,” and followed by questions leading to answers to the research questions of the study. It was not necessary for the participants to adhere strictly to the questions. New questions were developed for each participant during the interview or after the first interview to clarify and elaborate the details of participants’ experiences. The interview guide ended with an open-ended question that allowed the participants to give any additional information they wished to share. Prior to the initiation of this study, the personal and the HIV-related information sheet, as well as the interview guide, were approved by the advisory committee.

3. The investigator

In a qualitative study, the investigator is an important instrument because the investigator is the observer, the interviewer, and also the interpreter of various aspects of the inquiry (Streubert & Carpenter, 1995: 17). Therefore, the background

or the professional and personal experiences, as well as self-preparation in the research area of the investigator, are important to be revealed.

Professional experience

The investigator has been a nursing instructor for over 15 years, spending twelve years at the Christian College and over five years at Hua Chiew Chalermprakiet University. The investigator has experience in clinical teaching in medical and surgical wards at the Bangkok Christian Hospital, the Hua Chiew Hospital, and the Pramongkutklao Hospital. AIDS patients were usually found in these wards and were often assigned to nursing students under the investigator's instruction. Thus, the investigator had opportunities to take care of the patients with AIDS and to learn from them.

For the qualitative methodology, the investigator was trained in a course of qualitative research from the Faculty of Nursing, Mahidol University. The course created some skills of data collection through doing observations and interviews, writing field notes, performing content analysis with identifying themes, coding, and categorizing.

Personal experience

The investigator has a closed friend who was infected with HIV, and he died from AIDS about five years ago. He was a key person in his workplace to run the AIDS prevention project. The investigator sometimes worked with him and joined his projects. In some activities of the projects, the investigator had opportunities to meet some HIV-infected people who joined the projects as guests. They shared their experiences with us. They all found their lives better, more valuable, and more meaningful than they were before being HIV infected. Their lifestyles were changed in positive ways. They had worked as counselors and sometimes as speakers to help others who were in distress with HIV and to help other people prevent HIV infection. One of them who had been infected for about seven to eight years looked strong, tall, and healthy. He disclosed his HIV status to others and still worked in his workplace. That was the first time the investigator saw a positive side of HIV infection.

A few years ago, the investigator went to see the exhibition of HIV-infected people's photographs, sponsored by UNAIDS. The theme of the exhibition was "My Positive Life." There were 44 HIV-infected people who showed their

photographs in the exhibition. Thirteen people had been HIV-infected for more than ten years, seven people for nine years, and one with the longest duration of 18 years. The investigator met some people with HIV. Some had been infected for a few years, while others had been infected for more than ten years. All of them carried out AIDS activities of the NGOs. The investigator had a chance to talk with them about their health. A woman, who had lived with HIV infection for 11 years, said, “I feel healthier than I did before being infected.” I asked, “What do you mean when you say you are healthy?” She said she did not get sick as frequently as she did before being HIV-infected. Moreover, she felt herself worthier and that made her happy. It was very interesting to the investigator to see the long-term HIV-infected people looked healthy and lived longer with HIV, and this made the investigator wonder what kind of experiences they had as being HIV-infected people.

Self preparation

The investigator had read a lot of literature, both Thai and Western, which was relevant to the long-term HIV-infected people, as well as stress and coping of people with HIV/AIDS. The literature included biographies, stories of people with HIV/AIDS, research, news, and columns about HIV/AIDS in newspapers. By having some familiarity with these publications, the investigator has developed a rich background of information that sensitizes the investigator to what is going on with the phenomenon being studied (Strauss & Corbin, 1990: 42).

From reading and gaining experience with or relevant to an area being studied, the investigator has personal quality called theoretical sensitivity that is an awareness of the subtleties of meaning of data. The investigator also has insight and is able to give meaning to data, to understand, and to separate the pertinent from that which is not (Strauss & Corbin, 1990: 41-42).

Process of data collection

The process of data collection of this study was started in March 2001 and continued until April 2002. It was composed of the recruitment process, data collection method, and theoretical sampling. The followings are the description of these procedures.

Recruitment process

After receiving permission to conduct the research at the Bamrasnaradura Hospital, the investigator contacted the head nurse of the outpatient department, the head of the social welfare department and an official of the research center of the hospitals. These persons have direct contact with the HIV-infected clients of the hospital. The head nurse and the staff nurses of the outpatient department usually take a health assessment of the HIV-infected clients and do a brief interview of the clients' health history before sending them to the physicians. The official of the research center knows all of the HIV-infected clients who are recruited into the research projects of the hospital. These clients have follow-ups at the research center instead of the outpatient department. In addition, the head of the social welfare department meets the HIV-infected clients who have economic problems.

The investigator explicitly explained the purpose, the procedures of the study, and the inclusion criteria for the participants to the head nurse of the outpatient department, the official of the research center, and the head of the social welfare department. The investigator asked them to review their clients' date of HIV-infection diagnosis and make the initial contact with the HIV-infected persons who met the criteria. They initially asked the HIV-infected people whether they were interested in participating in this study. However, the investigator sometimes directly asked the HIV-infected people at the outpatient department to participate in the study because the head nurse and the staff nurses were busy.

As for the setting of the NGOs, the investigator directly contacted the managers of the NGOs and explained the purpose, the procedures of the study, and the inclusion criteria of the participants to them. The investigator asked the managers if there was any of their workers and clients who met the criteria. The managers were asked to make the initial contact with ones who met the criteria and ask them if they were interested in participating in this study. Moreover, the investigator directly contacted some long-term HIV-infected people, whom the investigator had known before, and asked them to participate in this study.

The head nurses, the head of the social welfare department, and the official of the research center of the Bamrasnaradura Hospital and the managers of the NGOs

introduced the potential participants who were interested in participating in this study to the investigator. Then, the investigator gave the potential participants a complete explanation of the study and answered any questions about the study they had. A consent form (Appendix C2) was given to the potential participants to read to understand the purpose and the procedures of the study. For some potential participants who were illiterate or had limited literacy, the investigator read the form to them. They were also asked to give the investigator a permission to see their anti-HIV and medical reports. They were assured that their participation was on a voluntary basis and the data would be kept strictly confidential. They were free to discontinue the participation at any time and to refuse to answer any questions they did not want to discuss.

After the potential participants agreed to participate in this study, they were asked to sign the consent form. Then the interviews were mutually arranged and data collection was performed. Later, some participants were asked if they knew their friends or someone else who had been HIV-infected for ten or more years. The participants were asked to make an initial contact to these persons and asked these persons whether they were interested in participating in this study.

Data collection method

In this study, data collection methods included interviews, general observation during the interviews, and reviews of medical records regarding HIV infection. Data collection and data analysis were conducted simultaneously until theoretical saturation of each category was reached. This meant (1) no new or relevant data seemed to emerge regarding a category; (2) the category development was dense; and (3) the relationships between categories were well established and validated (Strauss & Corbin, 1990: 188).

The participants were interviewed individually by the investigator in the private areas. The interview guide containing open-ended questions was used in the interviews. The investigator started with the general statement; "Tell me what has happened to you since you first learned you are infected with HIV." The investigator encouraged the participants to clarify and elaborate the details of their experiences by using probes and the questions listed in the interview guide. The interviews were audiotape-recorded with permission from the participants. At the end of the interview,

the investigator asked the participants if they had any question or anything about their experiences that they would like to share with the investigator. Finally, the participants were asked to give the data related to their personal background.

All of the participants were interviewed at least twice. Two participants were interviewed three times. These two participants were selected to capture more information for the density of the two-poorly-developed categories: “developing a warm family” and “preparing for terminal illness and death” and to verify the emerging theory.

The first interview lasted a period ranging from 30 minutes to two hours with an exceptional case of five hours. The average was approximately one and a half hours. The variation of the time was due to the setting of the interviews, the participants’ living places, the personality of the participants, as well as the richness and complexity of the information. In the hospital setting, the time of the interviews was shorter than that in the offices of the NGOs working on AIDS activities or other places. At the hospital, the interviews were conducted on the days the participants had a health follow-up. These participants had limited time for the interviews because several of them had to go to the bus stations in time to go back home in remote provinces, while some of them had to return to work on that day. However, the second interviews of these participants took more time. The investigator made appointments with them early in the morning before the opening hour of the hospital on the next follow-up date.

The interview of one participant took five hours. She worked and lived in the NGO office. She was a talkative person and had a systematic thought as well as an analytical skill. She had a lot of life experiences and her life had continuously changed since she had HIV infected. She described her experiences since she was young to explain the reason why she was HIV infected.

The second interviews lasted a period ranging from 30 minutes to two hours with an approximate average of one hour. The time spent in the second interviews was usually shorter than the first ones because the first interviews were rich and the second were conducted to clarify the data and validate the interpretation of the data and the emerging categories. However, in the cases that the first interviews were short and the information was not sufficiently rich, the second interviews might be longer.

The third interviews with two participants lasted one hour. They were conducted to fill some poorly-developed categories and to verify the developed theory. The total interview time for each participant ranged from 80 minutes to 8 hours, with an approximate average of two and a half hours.

During the interview, the investigator observed the general appearance of the participants, non-verbal behaviors such as facial expression, posture, gesture, and tone of voice, location, and the situation. After the interviews, the investigator immediately recorded all of the interactions and observations during the interviews in field notes.

The investigator received permission to study the medical records of the participants from the two hospitals--Bamrasnaradura Hospital and Ramathibodi Hospital. Only eleven participants' medical records were reviewed since they were the clients of these two hospitals whereas the other nine were not. The medical data such as the date of HIV infection diagnosis, the history of HIV related diseases, anti-retroviral medications, and laboratory tests were recorded in the personal and HIV related information sheet. Six of them had ten or more years of medical records, so the investigator could confirm their HIV-seropositivity of the past ten or more years. However, the others could not be confirmed because they were firstly diagnosed with HIV infection from other hospitals or clinics and came to these two hospitals a few years later. However, all participants knew their health history, their CD₄ and viral load level, as well as the medications including the anti-retroviral medications they received.

Theoretical sampling

In a grounded theory study, the initial sample for data collection is determined to examine the phenomenon where it is found to exist, that is persons with long-term HIV-infection that meet the criteria of the study. The data from initial data collection will be analyzed through content analysis and constant comparison method to elicit codes and categories. Then the emerging codes and categories will direct the further data collection, from which the codes and categories will be further theoretically developed with respect to their various properties and their connections with others until saturated. This process of data collection is called theoretical sampling (Chenitz, & Swanson, 1986: 9; Glaser, 1978:36).

Glaser (1978: 36) defined theoretical sampling as the process of data collection for generating theory whereby the analyst jointly collects codes, analyzes the data, and decides what data to collect next and where to find them, in order to develop the theory as it emerges. This process of data collection is controlled by the emerging theory. The aim of theoretical sampling is to sample events, incidences, and so forth that are indicative of categories, their properties, and dimensions, so that the investigator can develop and conceptually relate them. Thus, theoretical sampling ensures the noting of variation, process, and density (Strauss, & Corbin, 1990: 177).

Strauss and Corbin (1990: 176-193) suggested that the procedures of theoretical sampling differ according to the type of coding in which the investigator is engaged. In open coding, one engage in open sampling that can be done purposively or systematically. In this study, the investigator purposively selected the HIV-infected persons who met the inclusion criteria. During axial coding, relational and variational sampling was done to maximize the finding of differences at the dimension level. The investigator tried to find out the samples who had a variety of properties in terms of age, education, socio-economic background, marital status, the family's conditions, and occupation. In selective coding, the investigator conducted discriminate sampling to maximize opportunities for verifying the story line and relationships between categories and filling in poorly developed categories. Some participants, whose experience fell under the poorly developed categories, were selected. The additional interviews related to these categories were done with these participants. Moreover, the core category, the sub-categories, and their relations were verified with some selected participants. Sampling continued until theoretical saturation of categories was achieved. The categories were considered saturated when no new information seemed to emerge during coding, that is, no new properties, dimensions, conditions, actions/interactions, or consequences were seen in the data (Strauss & Corbin, 1998: 136).

Data Analysis

The tape-recorded interviews were transcribed verbatim by the investigator. The transcribed texts were read repeatedly to enable the investigator to become

familiar with the data which were then analyzed by the investigator. The investigator analyzed the data via the process of coding and used the constant comparative method of analysis, memos and diagrams writing throughout the analyzing process.

Coding process

Coding is the process of analyzing data. It represents the operations by which data are broken down, conceptualized, and put back together in the new ways. It is the central process by which theories are built from data. Coding process is composed of three major types of coding. These are open coding, axial coding, and selective coding (Strauss, & Corbin, 1990: 57-61).

Open coding

Open coding is the process of breaking down, examining, comparing, conceptualizing, and categorizing data. During open coding, the verbatim raw data were broken down into discrete parts, closely examined, compared for similarities and differences, and questions were asked. Each discrete incident, idea, or event was given a name that stood for or represented a phenomenon. Similar events and incidents were labeled and grouped to form categories. By this process, concepts were identified and developed in terms of properties and dimensions (Strauss, & Corbin, 1990: 61-74).

To demonstrate the process of open coding, an example is given here. The words of the participants were: *“After I knew that I was infected, I was scared of facing anybody. Even my friends, I didn’t go to see them. When my friends came to see me, I would hide myself. My relatives asked me to dine with them. I refused to meet everybody...Didn’t go anywhere...like I lived alone.”* These statements clearly indicated “avoiding meeting others” and “living with oneself.”

As a number of open coding proliferated, the investigator turned to examine and collapse codes into categories or higher level concepts. The previous example, “avoiding meeting others” and “living with oneself” were collapsed into “avoiding social contact” which then was conceptualized as one strategy of the category “Flight.” Once a category was identified, the investigator began to develop the category in terms of its specific properties, and then they became the definition of the category.

Axial coding

Axial coding is the process of relating subcategories to category and between categories. It is a complete process of inductive and deductive thinking. It is a set of procedures whereby data are put back together in new ways by making connections between a category and its subcategories and also between categories. The categories are specified in terms of the conditions that give rise to them; the context in which they are embedded; the action/interaction strategies by which they are handled, managed, carried out; and the consequences of those strategies (Strauss, & Corbin, 1990: 96-115). In the present study, the investigator looked for the answers to questions such as why, where, when, how, and with whom in the phenomena, and then the relationships among categories were uncovered.

Bringing process into analysis is also an essential feature of a grounded theory analysis. The investigator consciously looked for signs in the data indicating a change in conditions, and traced out what corresponding changes in action/ interaction that these brought. Then, the stages or phases of the process were indicated with an explanation of what made the process move (Strauss, & Corbin, 1990: 157).

Selective coding

Selective coding is the process of selecting the core category, systematically relating it to other categories, validating those relationships and filling in categories that need further refinement and development. This process develops a core category that is the conceptualization of a descriptive narrative about the central phenomena (Strauss, & Corbin, 1990: 116-142). During selective coding, the investigator validated the categories and their relationships with the participants, and then further refined them and their relations. The core categories were obtained through writing the story line, drawing diagrams, reviewing and sorting through memos, consulting experts, and doing member checks. Finally, the core category was a basic social psychological process explaining the process of fighting to live normally with HIV infection.

Memos and diagrams

Memos and diagrams are essential procedures in the data analysis process. They enable the investigator to keep an ongoing record of the emerging categories, relationships, and ideas about the findings. Memo refers to written records of

analysis related to the formulation of theory. In this study, four types of memos were used. First, methodological memos were used to record issues in sampling and data collection. Second, coded memos were used to record the actual codes, to explain the meaning of conceptual labels and to show their relation to the raw data. Third, analytic or theoretical memos were used to develop ideas about the emerging concepts and their relations to each other. Finally, summary memos were written for the whole set of the interviews with each participant so as to facilitate apprehension of the “whole picture” of the participants. Diagrams were visual representations of the relationships between concepts. Both memos and diagrams had been written since the beginning through the end of data analysis. They were useful for the description of the developed theory.

Protection of Human Subjects

Before entering into the study, the potential participants were informed with complete explanation and written description about the purpose, the method, the potential risks and benefits of participation in the study, the protection of confidentiality, and their rights as subjects. They were assured that their participation was voluntary. They were given opportunities to ask questions, and the investigator answered any questions about the study they had. A written consent was obtained once the individual decided to participate in the study. For some potential participants who were illiterate or had limited literacy the investigator read the written description in the consent form to them. A copy of the written consent was provided to each participant.

During the interviews, participants could ask questions, refuse to answer any questions they did not want to discuss, or stop the interview at any time. The interview continued only when the participants desired. In order to ensure the confidentiality of participants and data, the investigator transcribed the audiotape-recorded interviews by herself and the participants' name were replaced with code numbers. Other identifiers such as locations of interview or institutions were removed from the transcripts. All of the written data including notes were kept in separate secure files. A list linking the code numbers and the participants' name was accessible

only to the investigator. The list and the tapes containing interview data were stored in a secure file cabinet and were destroyed after the data were no longer needed for the purposes of the study.

Establishment of Trustworthiness

Trustworthiness is a basic issue related to how the investigator can persuade readers that the findings of an inquiry are worthy and worth taking into account (Lincoln, & Guba, 1985: 290). Lincoln and Guba (1985: 300) introduced four criteria for the trustworthiness of qualitative study. These criteria are credibility, transferability, dependability, and confirmability. These terms are equivalent to empiricist terms in quantitative research: internal validity, external validity, reliability, and objectivity, respectively. These criteria were used as guidelines to determine the trustworthiness of the present study.

Credibility

Credibility is the criterion against which the truth-value of qualitative research is evaluated (Lincoln, & Guba, 1985: 294-296). Qualitative research is credible when it presents a faithful description of the human experience. Lincoln and Guba (1985: 301-316) suggested many techniques to increase credibility of qualitative research findings. The investigator adopted some of these techniques in this study.

Firstly, prolonged engagement, the sufficient time to achieve certain purposes, was used to build trust. Trust is a developmental process, to demonstrate to the participants that their confidences will not be used against them (Lincoln, & Guba, 1985: 303). In this study, several interviews were conducted with each participant. Thus, the relationships between the investigator and the participants were enhanced, and hence the truth-value was increased. When the adequate trust and rapport were emerged, the participants shared their experiences openly. The investigator noted that in the second or the subsequent interviews, the participants usually shared their experiences in more detail and their confidential personal matters were revealed to the investigator.

Secondly, triangulation of different sources of information and different data collection modes were carried out. Interview, observation, and review of medical

records were used to collect the data. Triangulation of different investigators was also applied. Data analysis procedures of the first four cases were reviewed by an advisor who was an expert in grounded theory methodology and the overall analysis procedures were reviewed by another advisor. Finally, the analytic categories, the interpretations, and the conclusions were criticized by the advisory committee and a social worker who had experience in working with HIV-infected people for over ten years. Their comments were utilized for consideration and improvement of the developed theory as well.

Thirdly, member check is another technique that is crucial for establishing credibility (Lincoln, & Guba, 1985: 314). The data, analytic categories, interpretations, and conclusions were tested with participants. Member checks were used continuously in the course of the investigation. A summary of each interview was described to the participants during the next interviews. Any errors involving prior data were corrected, and some data were clarified after discussing with the participants. It also provided the participants opportunities to volunteer additional information. Moreover, the interpretation and conclusion of the study were tested and discussed with four participants. They eagerly examined the interpretation and conclusion. They shared ideas and gave suggestion to the categories' name and their relations, as well as gave more explanation of their experiences. The investigator considered their suggestions and used them in developing the theory.

Transferability

Transferability or fittingness appraises how well the working hypotheses or propositions fit into a context other than the original context of the study (Beck, 1993: 264). Thus, transferability depends on the degree of similarity between sending and receiving contexts (Lincoln, & Guba, 1985: 297). The investigator was responsible for adequately describing the original context of the study so that the readers could possibly make a judgement of transferability. In this study, a thick description that included the explanation of the participants' background, the process of data collection, as well as the sufficient and relevant contextual information of each stage of the participants' coping process was provided.

Dependability and Confirmability

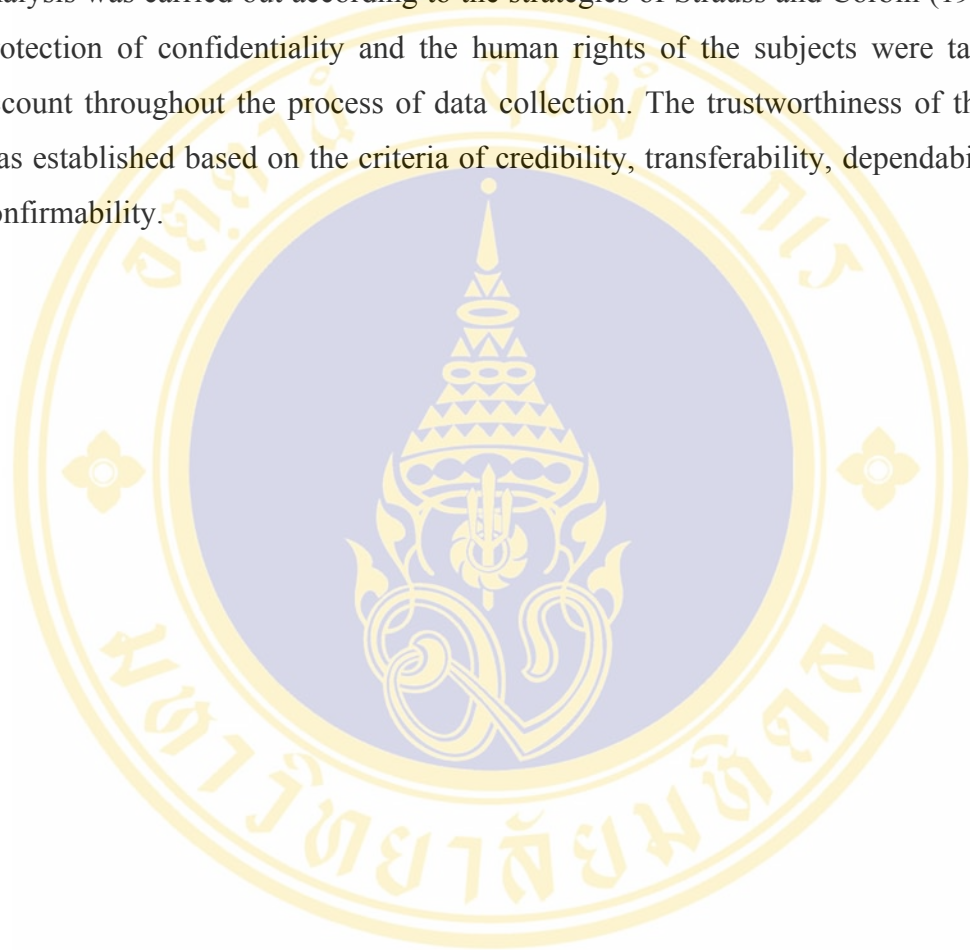
Dependability or auditability refers to the ability of another investigator to follow the decision or audit trail, which includes all of the decisions made by the researcher at every stage of data analysis (Beck, 1993: 264). Confirmability is a substitute criterion for objectivity or neutrality in qualitative research. The evaluation of confirmability is based on the characteristics of the data rather than on the investigator's characteristics. It refers to the findings themselves, not to the subjective or objective stance of the researcher (Lincoln & Guba, 1985: 323; Sandelowski, 1986: 34).

Lincoln and Guba (1985: 317-321) noted that an audit process can be used to ascertain both dependability and confirmability of the study. The investigator developed an audit trail for this study. Raw data were completely and systematically recorded or noted. Audiotapes, transcripts, and data analysis products were arranged and sorted. The advisors as auditors could attest the dependability of the study by examining the process of the inquiry and determining its acceptability, and also attest the confirmability by examining the data, findings, and interpretations and determining its accuracy. In addition, confirmability was ensured by the fact that the whole process of the study was coherent and the results of the study were logical. The participants' quotations were appropriately and adequately addressed to demonstrate that the findings were grounded in events, not personally assumed by the investigator.

Summary

A grounded theory study was conducted with 20 Thai people who had been HIV-infected for ten or more years to generate a substantive theory explaining their coping process with HIV infection. The setting for this study included the outpatient department, the research center, and the social welfare department of the Bamrasnaradura Hospital, Ramathibodi hospital, as well as the offices of the NGOs working on AIDS activities. The participants were firstly asked to participate in the study by the head nurse or the staff nurses, the official of the research center, the head of the social welfare department, or the officials of the NGOs, while some participants were directly contacted by the investigator. The data collection method included

interviews, general observation during the interviews, and reviewing the participants' medical records. Most of them were interviewed twice, but two participants were interviewed three times. The total interview time for each participant ranged from 80 minutes to eight hours, with an approximate average of two and a half hours. Data analysis was carried out according to the strategies of Strauss and Corbin (1990). The protection of confidentiality and the human rights of the subjects were taken into account throughout the process of data collection. The trustworthiness of this study was established based on the criteria of credibility, transferability, dependability, and confirmability.



CHAPTER IV

STUDY FINDINGS

The purpose of this study was to explore the coping process among Thai people with long-term HIV-infection. A substantive theory describing a basic social and psychological process by which these people cope with HIV-infection and the events in their lives after the infection was developed. It was entitled “The Process of Fighting to Live Normally with HIV-Infection.” This chapter describes the background of the participants and the process of fighting to live normally with HIV-infection.

Participant Background

The participant background includes demographic information and HIV-related information. Demographic information of the participants is presented in Table 1, while the HIV-related information is summarized in Table 2.

Demographic information

The participants in the study were 20 HIV-infected persons. Twelve participants were male, and eight were female. Three of the male participants were homosexual. Almost all of the participants were Buddhist. The participants ranged in age from 27 to 52 years old. The overall mean of the participants' age was 37.65 years with a standard deviation of 7.68.

In examining the educational level of the participants, it was found that ten participants had high school education, seven participants had vocational and university level education, and the rest (n=3) completed primary education. Half of the participants (n=10) were married or living together with their current spouses. Two of them had married before learning of their infection, and their spouses were

Table 1: Demographic information of the participants (n=20)

Demographic Information	frequency
Sex	
Male	12
Female	8
Age (range 27 - 52)	
< 30	2
30 - 34	5
35 - 39	6
40 - 44	2
45 - 49	3
≥ 50	2
Religion	
Buddhism	19
Islam	1
Educational Background	
Primary school	3
High school	10
Vocational school	5
University	2
Marital Status	
Single	5
Married	10
Widowed	4
Separated	1
Number of Children	
None	4
One	6
Two	4
Three	1
Occupation	
None	4
NGO activist	6
Businessperson	3
Employee	3
Government official	3
Vender	1
Income (baht/month)	
5,000 or less	3
5,001 – 10,000	7
10,001 – 20,000	5
More than 20,000	5

still not infected, whereas the spouses of the other eight of them were also infected. Five male participants were single. Three of the single male participants were those who were homosexual. Four participants were widowed. Their spouses had been HIV-infected as well and had passed away. Only one participant was separated from her husband, who was also HIV-infected. This participant got married after learning of her infection.

There were 15 participants who were married or used to be married. Eleven of them had children while the other four had not. The majority of them had one or two children. Five participants had children before finding out their infection. Three of them had their own children after they had the infection. One participant was pregnant at the time she found out she had HIV infection, and two adopted other infected people's children whose parents passed away. The ages of their children ranged between 1 and 25. Only one child, who was nine years old, was infected. Furthermore, the youngest girl, who was one year old, did not know her HIV-infection status. She looked healthy and had never been ill except for some common colds.

Of the nine participants who had no children, five were single. Two used to have children, who had died several years earlier, and the other two did not have children though they were married.

The occupations of the participants were varied. Six participants worked for the non-governmental organizations (NGOs) working on AIDS activities. Other occupations included businesspersons, employees, and government officials, each of which was made up of three participants. One participant was a vender, a street seller who sold petit accessories. Four participants did not work. Also, two of them were supported by a social organization, and the other two lived with their family and did housework for the family.

In addition, the participants' income, which included the income of their spouses for those who were married, varied widely. It ranged from less than 5,000 Baht/month to about 40,000 or 50,000 Baht/month. Ten participants had income lower than 10,000 Baht/month, while the others had above 10,000 Baht/month. Three participants, who had income less than 5,000 Baht/month, were supported by a social organization or their families (siblings). Finally, there were three participants, who

had income between 5,001 and 10,000 Baht/month, reported occasionally inadequate money to cover their family's and their own expenses.

HIV-related information

The period of time that the participants were aware of their HIV-status ranged from 10 to 16 years. The majority of the participants (n=14) had been aware of their HIV infection for ten years. Fifteen participants contracted the virus through sexual contacts; 13 of them were heterosexual and two were homosexual. Three participants contracted the virus through intravenous drug use. The remaining two reported that they were not sure how they had HIV infection.

Table 2: HIV-related information of the participants (n=20)

HIV-related information	frequency
Awareness of HIV status	
10 years	14
11 years	2
15 years	2
16 years	2
Mode of HIV Transmission	
Sexual contact	
Heterosexual	13
Homosexual	2
Intravenous drug use	3
Unsure	2
History of HIV-related diseases	
Yes with minor illness	5
with serious illness	7
No	8
CD ₄ level (cells/ μ l)	
Less than 200	7
200 – 499	9
Equal or more than 500	3
Never had the test	1
History of anti-retroviral therapy	
Yes regularly and continuously	4
irregularly or discontinuously	4
Short period use and cessation	7
No	5

Of the participants who were infected by heterosexual contact, six were male and seven were female. Five of the male participants were infected by prostitutes, and one by his girlfriend. As for the female participants, four of them were infected by their husbands, two were infected as prostitutes, and one was infected by her ex-husband.

The two male participants who were not sure of how they contracted the virus worked in a risky situation. One worked as a volunteer who transferred the injured people to the hospital, and the other worked as a person who took care of patients, including AIDS patients. At that time, they did not know how to protect themselves from being infected. Thus, they were not sure whether they had contracted the virus through their work or through sexual contacts.

In terms of the histories of HIV-related diseases, twelve participants had experienced the diseases, while the other eight participants never had. Five of the participants, who had got HIV-related diseases, had only some minor illnesses such as diarrhea, skin problems, oral candidiasis, and herpes zoster for which they needed no hospitalization and were still able to care for themselves. The other seven participants had serious illnesses, the opportunistic infections, for which they needed hospitalization or treatment and care from others. All of the participants, who never had HIV-related diseases were those who had learned their HIV-status for ten years.

Most of the participants had health check-ups and also followed up their CD₄ levels. The CD₄ levels, presented in Table 2, were mostly tested in the year of the interview. Four persons had the test one year before the interview, and two had it a few years ago. Their CD₄ levels were widely different ranging between 1 and 800 cells/ μ l. Three participants had CD₄ levels above 500 cells/ μ l. They all looked healthy and had never had HIV-related diseases. One of them had taken anti-retroviral (ARV) drugs for one year, whereas the other two had never taken any ARV drugs.

The majority of the participants (n=15) had experience taking ARV drugs. Only four of them had taken the drugs regularly and continuously for a period of time varying from one to ten years. Four of them had intermittently taken the medicines for a few years and discontinued use. Moreover, seven of them had tried the drugs for a short period, ranging from just a few weeks to a few months, and then stopped taking the medicines because they could no longer tolerate the adverse effects. The other five

participants had never taken ARV drugs. Some of these participants refused to get the therapy because they thought that it would harm their bodies.

The Process of Fighting to Live Normally with HIV-Infection

The core category emerging from data analysis was the process of fighting to live normally with HIV-infection. The word “fight” is equivalent to the word “*su*” (สู้) in Thai. It means to struggle against or to overcome their emotional suffering and many problems or difficulties. “Living normally” is a state that these participants went on with their life as a normal person living in the society. The process of fighting to live normally with HIV-infection took place under the condition of being a stigmatized disease: HIV infection or AIDS, which is viewed as life-threatening and disgusting disease. The process also took place under the context of social pervasive fear of the disease, and social discrimination and prejudice to HIV-infected people. Therefore, it is the process that the participants had to continuously make both cognitive and behavioral efforts to struggle against or overcome their emotional suffering as well as many problems or difficulties in their lives, which had been created from having a stigmatized disease, in order to achieve a state of living normally.

The analysis of the interviewed data revealed that the process of fighting to live normally with HIV-infection consisted of four stages including flight, pulling oneself together to fight, fighting for existence, and living normally. In the flight stage, the participants avoided facing or ran away from the situations related to the infection. The second stage, pulling oneself together to fight, was a period that the participants turned themselves from flight to a ready state to fight for living. The third stage, fighting for existence, was a stage where the participants worked very hard to overcome many events or difficulties for continuing their lives and attaining their purposes in living. Finally, living normally was a state that they went on with their lives as a normal person living in the society. The participants’ action and interaction strategies that were carried out in the process involve cognitive, emotional, behavioral, and spiritual dimensions. The participants usually moved through these

stages respectively after they had been diagnosed with HIV-infection. These stages were not definitely separated from one another. Rather, they often overlapped. In this study, each stage was analyzed in terms of causal conditions, contextual conditions, intervening conditions, action and interaction strategies, and consequences, which are concluded in Table 3. The process of fighting to live normally with HIV infection is shown in Figure 1, and the details are subsequently described.



Table 3: The process of fighting to live normally with HIV infection

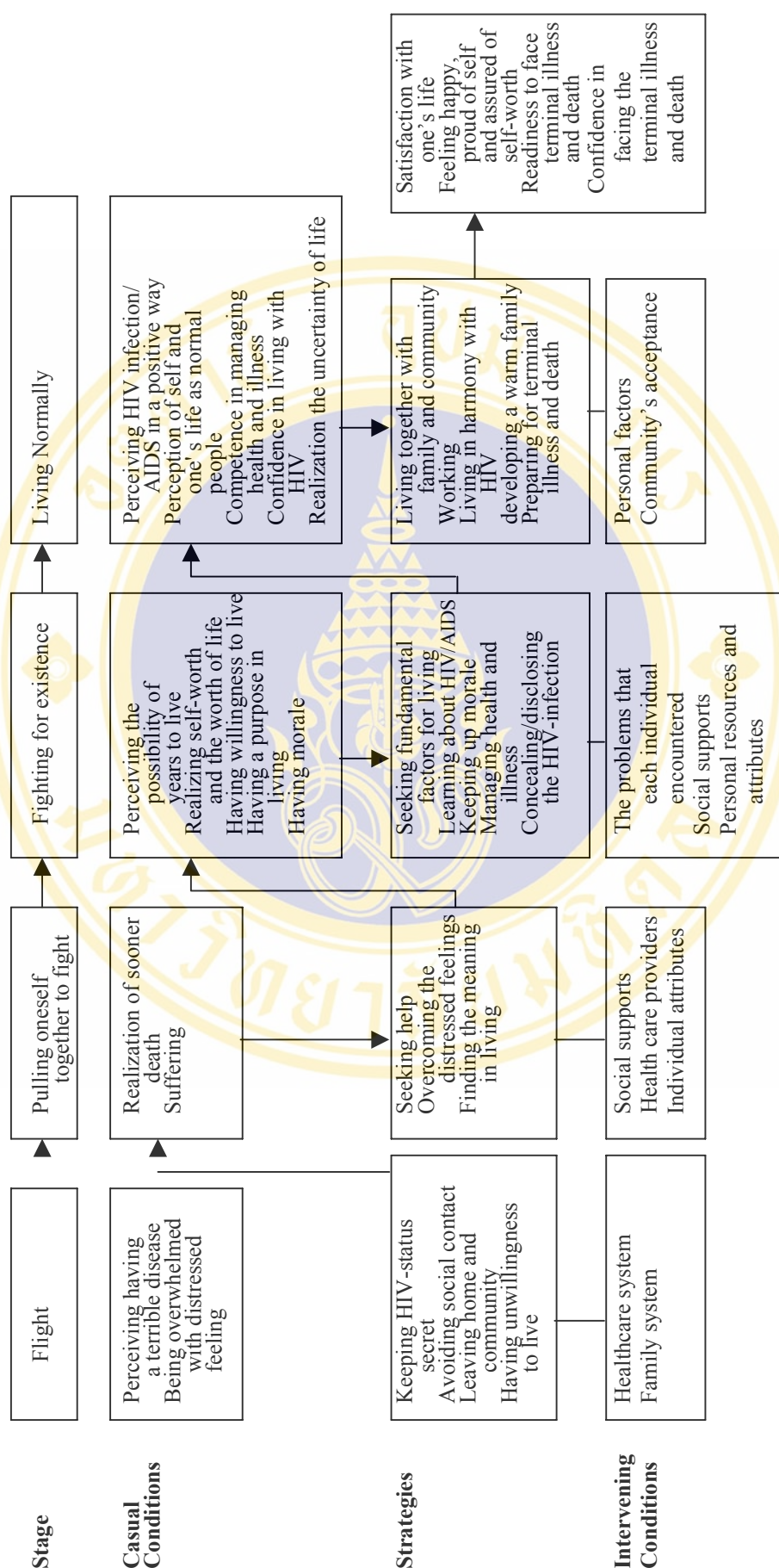
Conditions	Action/Interaction Strategies	Consequences
Stage One: Flight <u>Causal conditions</u> Perceived of having a terrible disease Being overwhelming with distressed feelings <u>Contextual conditions</u> The Act 1985 Negative social images of HIV/AIDS Negative social reactions to HIV-infected people <u>Intervening conditions</u> Healthcare system Health center setting The means of presenting the result of HIV-blood-test Discrimination in providing care Family system Relationships among family members The participants' role in the family	Keeping HIV-status secret Avoiding social contact Leaving home and community Having unwillingness to live Not performing daily ordinary self-care Having a suicidal thought	Suffering Encountering the difficulties in living
Stage Two: Pulling oneself together to fight <u>Causal conditions</u> Suffering Realization of sooner death <u>Contextual conditions</u> Negative social images of HIV/AIDS Negative social reactions to HIV/AIDS <u>Intervening conditions</u> Social supports Family HIV-infected groups or friends Healthcare providers Individual attributes	Seeking help from Family Health centers or healthcare providers HIV-infected friends or groups Respected spiritual matters Overcoming the distressed feelings Alleviating the feelings <i>Tham jai</i> Finding the meaning in living Considering about one's situation Realizing the worth of self and life Creating a purpose of life	Feeling relief, less fearful, and less anxious Changes in perception of HIV/AIDS Having willingness to live Realizing self-worth and the worth of life Having hope Having morale Having a purpose in living

Table 3: The process of fighting to live normally with HIV infection (cont.)

Conditions	Action / Interaction Strategies	Consequences
Stage Three: Fighting for Existence <u>Causal conditions</u> Perceiving the possibility of years to live Realizing self-worth and the worth of life Having willingness to live Having a purpose of life Having morale <u>Contextual conditions</u> Social discrimination / prejudice Gradual development of HIV-infected groups and social organizations working on HIV/AIDS <u>Intervening conditions</u> The problems that each individual encountered Social support Personal resources and attributes Socioeconomic status Education Occupation / vocational skill Persistence Fighting spirit	Seeking fundamental factors for living Mobilizing resources Finding jobs Working hard Learning about HIV/AIDS Learning about the nature of HIV/AIDS Learning about the factors affecting health and disease progression Learning to manage the disease Managing health and illness Keeping well Seeking healthcare Managing the physical illnesses Keeping up morale Concealing/disclosing the HIV-infection Concealing from some people Disclosing to others	Meeting basic physical needs Increasing sense of self-worth Feeling proud of self and being satisfied with life Perceiving HIV infection in a positive way Having competence in managing health and illness Having confidence in living with HIV

Table 3: The process of fighting to live normally with HIV infection (cont.)

Conditions	Action / Interaction Strategies	Consequences
Stage Four: Living Normally <u>Causal conditions</u> Perceiving HIV infection / AIDS as: a chronic disease, not a disgusting disease, a company living together, and an opportunity for life Perception of self and one's life as normal people Competence in managing health and illness Confidence in living with HIV Realization of the uncertainty of life <u>Contextual conditions</u> Full development of HIV-infected groups, organizations, and network around the country Increase in community understanding with HIV-infected people <u>Intervening conditions</u> Personal factors The community acceptance	Living together with family and community Working Living in harmony with HIV Developing a warm family Preparing for terminal illness and death	Satisfaction with one's life Feeling happy, proud of self, and assured of self-worth Readiness to face terminal illness and death Confidence in facing the terminal illness and death

Figure 1: The process of fighting to live normally with HIV infection

Stage One: Flight

Flight, the first stage of the process of fighting to live normally with HIV-infection, began after the participants had an awareness of their HIV-infection. In the flight stage, the participants tried to avoid facing or run away from the situations related to their infection. They also tried to withdraw themselves from social interaction. The causal conditions that led the participants to perform these actions were the perception of HIV infection or AIDS as a terrible disease and being overwhelmed with distressed feelings including hopelessness, fear, and anxiety.

Perception of HIV infection: A terrible disease

The participants mostly perceived HIV infection or AIDS as a terrible disease that was life threatening and disgusting. They thought that HIV infection or AIDS was incurable and they could be alive for only a short time. Moreover, they realized that the community and society were disgusted with HIV-infected people as well as in fear of the disease being transmitted from the infected persons. As a result, they perceived great harm, loss, and threat to themselves. The following participants' quotations are examples of the participants' perception of HIV infection or AIDS:

I knew it was a severe disease. I would definitely become skinny and die as there was no medicine to cure it. (9/2: p2, 3-4)

รู้ว่าเป็นโรคร้ายแรง ต้องตายแน่ ต้องผอม ยังไม่มียารักษา (9/2: p2, 3-4)

I knew that those who had HIV would die. Everyone would be disgusted. We couldn't live in the society. This was the way I thought.

หนูทราบว่าโรคติดเชื้อ(HIV) แล้วต้องไม่มีชีวิตอยู่ ทุกคนจะต้องรังเกียจ สังคม...อยู่ไม่ได้ละ หนูคิดอย่างนี้ (20/1: p2, 28-29)

Being overwhelmed with distressed feelings

At the time when they were informed of the diagnosis, they were shocked for a moment or several hours. They reacted somewhat differently. Some participants were frightened, numbed, stunned, confused, and felt like losing of consciousness for a while as indicated by the participants as follows:

At the moment I knew I had been HIV-infected, my whole body went numb. It is difficult to explain. It was numb from head to toe. (15/1: p2, 1-2)

ตอนที่รู้ที่เราติดเชื้อ เราเข้าไปทั้งตัวเลย มันพูดไม่ถูก ชาตั้งแต่หัวจรดเท้า (15/1: p2, 1-2)

At that time I was blurred...I cannot exactly explain it. It seemed I was unconscious... It was all blurry...I thought all the time what I could do. Why did it have to be me? (16/1: p6, 8-17)

ตอนนั้นเบลอไปหมดเลย ... มันบอกไม่ถูก มันเหมือนไม่รู้สึกร่าง ... มันมัวซัวไปหมด ... สมอง คิดอยู่ตลอดเวลา ว่าเราจะทำยังไง ทำไมต้องเป็นเรา (16/1: p6, 8-17)

After the shock had calmed down, the participants were overwhelmed with distressed feelings including sadness, hopelessness, fear, and anxiety. They were upset and cried. They thought they would die within a few days to a few years. They lost self-confidence to continue what they were doing. They also felt desperate. All of their hopes were instantly destroyed. Their future seemed to be filled with gloom, and they could not find the solution to their problems. They felt fearful and anxious about those threatening events that would probably happen to them and their family in the near future. The participants suspected that other people might know their HIV-status though they had not disclosed it to anyone. They were in fear of being disgusted and abandoned, then they would lose their relationships to the significant others. The participants expressed their thoughts and feelings after they had just learned they had HIV as follows:

I felt very gloomy...I repeatedly thought and couldn't find the solution...My dream was completely tumbled down. I must die within two years. Whatever I saw and wherever I looked it was unpleasant, not bright, but depressing. I felt desperate...didn't want to do anything...like I gave up my life. Since it was like this, I wondered why I should live. (16/2: p2, 12-24)

รู้สึกมีดมนมาก ... ครุ่นคิดตลอดเวลา แล้วหาทางออกไม่ได้ ... สิ่งที่เราคาดหวังไว้ในอนาคตมันพังทลายไปหมดแล้ว เราจะต้องตายภายใน 2 ปีนี้ มองอะไรไปทางไหนมันก็ไม่สวย ไม่สว่างไสว มีแต่เรื่องหดหู่ทั้งนั้น หมกอาลัยตายอยาก ... ไม่อยากทำอะไร เหมือนกับยอมแพ้กับชีวิต ในเมื่อมันเป็นอย่างนี้แล้ว ก็มีความรู้สึกว่าจะอยู่ไปทำไม (16/2: p2, 12-24)

At that time I was still, like getting a shock...I felt anxious about how I could live with my family and with the society. It was a disgusting disease... My skin would become bruised with many spots (skin lesions) or something like that. At that time I thought so and was anxious. (1/1: p2, 1-18)

ในตอนนั้นก็รู้สึกนิ่งไป จะเรียกว่าเหมือนคนอยู่ในอาการช็อกก็ว่าได้ ... มันรู้สึกกังวลว่า เราจะใช้ชีวิตอยู่ยังไง จะอยู่กับครอบครัวกับสังคมต่อไปยังไร มันเป็นโรคที่น่ารังเกียจ ... อีกหน่อยมันจะต้องเฟอะพะเป็นดอกเป็นดวงอะไรอย่างนี้ ตอนนั้นเข้าใจแบบนั้น แล้วก็กังวล (1/1: p2, 1-18)

The participants also anticipated the fearful events in the future and the consequences of HIV infection. "To be sick" was mostly mentioned as an anticipated dreadful situation. It meant to suffer with unpleasant symptoms, to be disgusted, to be disabled, to be the others' burden, to have more expenses, and to be known by others

that they were AIDS. Then, other people would reject them. If that time finally arrived, how could they live in their family, community, and society? Some participants were worried about the expenses if they were sick. Some participants were anxious about their family as well. They were afraid that their family might get into trouble because other people would be disgusted and reject their family, too. Some participants were worried also about how their parents and kids would live if they had passed away. The participants were overwhelmed with these distressed feelings. They thought circuitously all hours about their fears and anxiety, and they then experienced confusion, insomnia, and headache. The following accounts are the participants' quotations expressing their worries at that time:

If I were sick, became worse, and got the sores, I thought I would be like what I had seen from the media, and I couldn't live long. I didn't want to be suffering... I would be skinny, couldn't walk, and couldn't eat. I didn't want to be like that... I didn't want to be my parents' burden... I want to die. (6/2: p3, 3-12)

ถ้าเพื่อเราป่วย เราทรุด มีแผลพุพอง นึกถึงว่าเราต้องเป็นอย่างนั้น ตามที่เห็นจากสื่อที่ออกมา และจะอยู่ได้อีกไม่นานก็ต้องตาย เรารู้สึกไม่อยากจะทรมาน ... ผมแบบเดินไม่ได้ กินก็ไม่ได้ ไม่อยากเป็นอย่างนั้น ... ไม่อยากจะเป็นภาระของพ่อแม่ที่ต้องดูแล ...อยากจะไป (6/2: p3, 3-12)

When I knew that I had HIV infection, I thought about how my mom could live and how I could live, from which source I could get the money to pay for the medical expenses. (12/1: p1, 25 – p2, 1)

ตอนที่รู้ผลว่าติดเชื้อ ก็คิดอยู่อย่างหนึ่งว่าแม่จะอยู่ยังไง แล้วตัวเราจะอยู่ยังไง จะเอาเงินที่ไหนมาเป็นค่ารักษาพยาบาล (12/1: p1, 25 - p2, 1)

If other people knew that I had AIDS, ...my family would certainly suffer hardship ... They would be disgusted. So, how could mom live? (2/1: p10, 14-16)

ถ้าชาวบ้านรู้ว่าเราเป็นเอดส์ ... ที่บ้านเราต้องแย่นะเลย ... เขาจะรังเกียจเอา แล้วแม่จะอยู่ยังไง (2/1: p10, 14-16)

At that time I thought about how long I could live...How could my children grow up? If I passed away, what should they do? Everyone would be in trouble...my mom, my children...My wife had only 2000-Baht salary. It wasn't sufficient, so how could she take care of the children? Although I had about 4000-Baht salary, there was no savings. So, how could my children live? (13/1: p4,22 – p5, 8)

ตอนนั้นผมคิดว่า ผมจะอยู่ได้อีกนานเท่าไร ... คิดว่าลูกจะโตยังไง ถ้าผมเป็นอะไรไป จะทำยังไงอะไรๆ มันก็ลำบากไปหมด ไหนจะแม่ ไหนจะลูก ... แฟนเงินเดือนแค่สองพันบาท มันก็ไม่พอกิน จะไปเลี้ยงลูกรอดหรือ ผมเงินเดือนสี่พันกว่า เงินเดือนผมยังไม่เหลือเลย แล้วลูกๆ จะอยู่ได้ยังไง (13/1: p4, 22 - p5, 8)

Contextual conditions

The contextual conditions of that time (over ten years ago) were the negative social images of HIV infection and AIDS as well as the negative social reactions to HIV-infected people. The negative social images of HIV infection and AIDS were the result of the dreadful mass media. HIV infection and AIDS were viewed as an incurable disease, a disease of death and a highly contagious disease. The image of persons with HIV or AIDS was horrible, deviant, or bad. Thai people reacted to HIV-infected persons with great fear and disgust. Therefore, families and community usually rejected the HIV-infected persons. The participants described the images of HIV-infected persons in the media and social reactions to HIV-infected persons at that time as follows:

The media was very aggressive. Just like a picture of horror, [AIDS patients] looked so skinny like a zombie or ghost. Those who had the sores on their body looked madly awful... It was an aggressive media and the picture was horrendous. All the words used in the advertisement sounded ruthless such as “promiscuous,” “drug-addicted”... All of these words were directly insulting. (21/2: p1, 7-12)

สื่อออกมาแบบแรงๆ เป็นภาพที่ แห้งก็แห้งแบบผิวดองเหลือง แห้งแบบหนังหุ้มกระดูก ที่เป็นแผลก็แบบออกดอก แบบน่าเกลียดมากๆ ... เป็นสื่อที่แรง ... เป็นภาพที่แรงมาก คำที่แพร่ออกมาก็เป็นคำที่แรง ส่วนทางเพศ มั่วเข้ม มั่วยาเสพติด เป็นคำที่ประณามตรงๆ (21/2: p1, 7-12)

In the village there had just been a funeral of an [AIDS] infected man ... His mother was an instant-food seller and she couldn't sell anything. She had to move away then. (2/1: p10, 17-20)

ในหมู่บ้านมีคนเพิ่งตายคนแรกด้วยโรคนี [AIDS] ... แม่เขาขายกับข้าว กับข้าวขายไม่ได้ แม่เขาต้องย้ายหนี (2/1: p10, 17-20)

Another contextual condition was the use of the “Monitoring and Controlling Patients Who Caught Serious Infectious Diseases” Act 1985 in Thai society. According to the Act, HIV-infected or AIDS patients were those who had to be monitored, controlled, and looked after by public health officials in order to control and prevent the epidemics of AIDS in the community. Any community which had HIV-infected or AIDS patients living there had to inform public health officials. Any hospitals which detected HIV-infected patients had to inform the Ministry of Public Health in order to monitor those who were infected. The public health officials would monitor those HIV-infected people, who were reported to the Ministry of Public Health and call on them at home and in their community. Thus, their infection would

be revealed to the family and community. This Act caused HIV infected persons and their family a lot of sufferings. They were rejected and unable to remain in the community. There was a demand to rescind this Act; hence, in 1990 it was rescinded.

Two participants, a 39-year-old female and a 48-year-old male, found out that they were HIV positive during the period of the Act (1985-1989). The adversities in their lives were the results of this Act. The female participant, who got the virus from her husband, was pregnant and had an HIV blood test at the antenatal clinic in 1987. One month later, healthcare personnel came to her home in which she lived with her parent-in-law. She told her story at that time:

At that time I was about 4-month pregnant, so I went signing up for pre-natal care. The doctor said there had been a lot of people living with AIDS and asked if I wanted to have a blood test and suggested so. A month later...the doctor visited my parent-in-law's house and asked for me ... I was frightened ... The doctor said I had AIDS. (8/1: p1, 4-12)

ตอนนั้นท้องประมาณสี่เดือนก็ไปฝากท้อง หมอเขาถามว่า เอ็ดส์เป็นกันเยอะแล้ว เจาะเลือดมัย หมอก็บอกให้เจาะเลือด ไปๆมาๆ ประมาณเดือนกว่า หมอมาที่บ้านพ่อแม่สามี บอกว่าคนไหนชื่อ ... ก็ตกใจ ... คุณหมอบอกว่าเป็นเอ็ดส์แล้ว (8/1: p1, 4-12)

Another male participant had an accident with mild injury in 1985. He went to a health center and had an HIV blood test. Although he had been told he had HIV since that time, he did not believe it and was not concerned about it. He thought that people with HIV must be sick and have symptoms as seen in the media, but he was still healthy. A few months later he could not deny it anymore when a healthcare personnel visited him at home and declared his HIV status. By this time his family and the community knew his HIV status as well. Then, the community rejected him and his family. He said the following:

That day I went out to work as usual and came back in the evening. Nobody said anything.... The next morning I went shopping for food for mom and for myself. At the store...the seller said, "Don't get in.... Just tell me what you want. I'll get it to you." I asked her what happened. She replied, "Please keep out. People are scared of you. Yesterday there was a doctor from public health who said you have AIDS." (21/1: p1, 21- p2, 4)

วันนั้นผมไปทำงานตามปกติ เช็นกลับมาที่ไม่มีใครว่าอะไร เช้าขึ้นมาผมก็ไปซื้อกับข้าวให้แม่ แล้วใส่ปิ่นโตไปทำงานด้วย แต่พอไปถึงร้านค้า ... แม่ค้าบอก "เอ็งไม่ต้องเข้ามาในร้าน เอ็งจะเอาอะไร บอกมา เดี๋ยวจัดให้" ผมถามว่า เกิดอะไรขึ้น เขาบอก "เอ็งไม่ต้องเข้ามาหรอก คนเค้ากลัว เพราะเมื่อวานนี้มีหมอจากสาธารณสุข เข้ามารับเอ็งเป็นเอ็ดส์" (21/1: p1, 21- p2, 4)

Action and interaction strategies

The participants' action and interaction strategies in the stage of flight were keeping HIV status a secret, avoiding social contact, leaving home and community, and having unwillingness to live.

Keeping HIV status a secret

Keeping HIV status a secret referred to an action of not telling the HIV-status to anyone. In this study, 13 participants were informed of the HIV-blood test result personally. For the other five, their HIV status were disclosed firstly by healthcare personnel to others such as their parents, their siblings, and in two cases to the community. Nine of the 13 participants were in doubt whether they ought to tell their families or friends about their HIV status. Firstly, they decided to conceal their HIV status from everyone even their parents, families, and close friends. These participants kept their HIV status a secret for different reasons and conditions. Some were afraid that their families and friends could not accept them and they might reject them. Some did not want to make their parents or families worry and feel sorry for them. Therefore, keeping their HIV status a secret was a way to make themselves feel safe, or not feel worse. These participants revealed their situations:

After receiving the blood test result I kept it as a very, very top secret...I wouldn't tell anyone. And I planned to keep it with just myself forever. Couldn't tell anybody because I was not sure whether they would still love me... I would tell it only to the doctors and nurses... I didn't tell anybody even my friends, relatives, and my husband. (18/1: p2, 7-20)

หลังจากทราบผลเลือด หนูเก็บเป็นความลับมากมายนะ ... ไม่ยอมบอกใครทั้งนั้น จะเก็บตลอด มันพูดไม่ได้ เพราะมันใจหรือว่าเขารักเรา ... หนูจะพูดกับเฉพาะหมอ พยาบาล ... แต่เพื่อน พี่น้อง หนูไม่บอกกับใคร แฟนหนูก็ไม่บอก (18/1: p2, 7-20)

If I had told Dad and Mom previously, they wouldn't let me suffer alone. They would try to find a way to cure me. But I feel like...I shouldn't have made my parents worried. So I decided not to tell anyone in my family. (14/1: p4, 18-21)

ตอนนั้นถ้าผมบอกพ่อกับแม่ ยังไงเขาก็คงจะไม่ปล่อยลูกเขาอยู่แล้ว ยังไงเขาก็ต้องหาทางรักษาผม ที่นี้ผมแบบว่า...ผมไม่น่าทำให้พ่อแม่ผมเดือดร้อน ผมก็เลยไม่บอกใครเลยในบ้าน (14/1: p4, 18-21)

Avoiding social contact

Avoiding social contact meant a set of actions by which the participants try to keep themselves away from other people because of the thought that others knew their HIV status or the fear that their HIV-status would be revealed

to others. Avoiding social contact included living to oneself and avoiding meeting and joining with others. Some participants quit their jobs and others quit their studies even though they had been studying in the last semester of the vocational study. Several of them stayed in their living rooms. Some continued their work and tried not to join their workmates. During that time they suffered and felt loneliness. The following statements are the participants' accounts indicating their attempt to avoid social contact:

I dared not go out of my home for months. Then I quit my job. I feared that other would know (about my infection). (3/1: p2, 6-7)

ไม่กล้าออกจากบ้านเป็นเดือน แล้วก็ไปลาออกจากงาน กลัวคนอื่นรู้ (3/1: p2, 6-7)

After I knew that I was infected, I was scared of facing anybody. Even my friends, I didn't go to see them. When my friends came to see me, I would hide myself...My relatives asked me to dine with them. I refused to see everybody...Didn't go anywhere...like I lived alone. (20/1: p2, 29 – p3, 3)

พอทราบว่าติดเชื้อ หนูไม่กล้าจะเผชิญกับใครเลย แม้แต่เพื่อนก็ไม่ไปหา พอเพื่อนมาหา ก็หลบ ... ญาติพี่น้องเรียกไปทานข้าวด้วย เราปฏิเสธหมดทุกคนเลย ... จะไม่ไปไหน ... เหมือนเราอยู่ตัวคนเดียว (20/1: p2, 29 – p3, 3)

The investigator questioned, “Why did you dare not face others?” One participant replied, “Others must have known I was infected with HIV. Someone who worked in the hospital would tell them. So, I didn't want to or dared not talk to anyone.” (20/2: p1, 11-12)

Leaving home and community

Over ten years ago, Thai people were fearful of HIV/AIDS, and believed that they might easily contract the virus through casual contacts with those who had HIV. Therefore, people in the community rejected the participants whose HIV statuses were disclosed to them. They also rejected these participants' families. These participants and their families could not live or work in the community and had to leave. For example, a male participant was aware of his HIV infection in 1986 and the community concurrently knew it as well as a result of the “Monitoring and Controlling Patients Who Caught Serious Infection Diseases” Act 1985. The community rejected not only him but also his family, and then he needed to go away from home as clearly shown in his statement:

At that time I was not welcome to society. When I entered a football field, with lots of people playing joyously, only a ball and I were left... The others had already run away. There was no friend who loved me. Those who worked

together also abandoned me and made my family face problems. For example, we couldn't talk to anyone. Everybody felt scared ... Scared that my relatives could be the virus carrier ... It wasn't only me who was unwelcome but the whole of my family was also. They were afraid...madly afraid of us. Did they hate me? No, they didn't, but they feared me. The neighbor's children also bullied my son and daughter. Their eyes and lips were swollen... My children said those bullies teased both them and me. They were teased that Daddy was AIDS infected so they fought those bullies... What I could do was to move out of home and bring my children with me. All I could do was only escaping from that point in order to let my family remain there...because I could do nothing against the society. (21/1: p1, 21 – p3, 1)

สังคมช่วงนั้นปิดสนิทเลยสำหรับผม พอเดินลงไปในสนามบอล เล่นกันเฮฮาๆกัน ผมลงไปเหลือผมกับลูกบอล เพื่อนหนีหมด เพื่อนฝูงที่รักกันก็ไม่มี ไอ้ที่ทำงานด้วยกันก็ไปกันคนละทิศละทาง ทำให้ครอบครัวผมมีปัญหา ก็เอาไปคุยกับใครก็ได้ ทุกคนกลัว กลัวว่าญาติพี่น้องของผมจะเป็นสื่อ เป็นพาหะพาไวรัสตัวนี้ไปให้เค้า ... สังคมปิดไม่ได้ปิดเฉพาะผม ปิดทั้งครอบครัวเลย เค้ากลัว คนเค้ากลัวมากๆ ถามว่าเค้าเกลียดมั๊ย เค้าไม่ได้เกลียดหรอก แต่เค้ากลัว ลูกชายผมลูกสาวผมก็โดนเด็กแถวนั้นรังแก ตาแตก ปากแฉ่ ... ลูกบอกพวกนั้นมันล้อพ่อ ล้อหนูว่า พ่อเป็นเอดส์ หนูไม่ยอม หนูก็เลยตีกับเค้า ... สิ่งที่ผมทำก็คือ ผมต้องออกจากครอบครัว ออกจากบ้าน โดยหอบหิ้วลูกไปด้วย ผมก็ได้แต่หนีออกจากตรงนั้นเพื่อให้ครอบครัวได้อยู่ตรงนั้น ... เพราะผมปะทะอะไรกับสังคมตรงนั้นไม่ได้อยู่แล้ว (21/1: p2, 10 – p3, 1)

Of the participants whose families learned about their HIV-status, several were abandoned. Their families were in fear of contracting the virus, facing social rejection, or being an object of disgust if people in the community knew the participants' HIV status. In short, they did not want the participants to live with them. The participants realized that they might cause trouble to their family. Therefore, they accepted the urge to go away from home. This can be seen from the following quotation.

Everybody in my house knew I had AIDS. They said I couldn't live in their house anymore. I must live in another place...They asked how they could live if I still lived with them. What would happen to the whole family's reputation? My cousins were teachers and all of them were government officials, so they felt scared. I told them that it was all right. I would take full responsibility for my life. It's better for me to die alone than let all my family experience hell on earth. (2/1: p14, 9-18)

ทุกคนในบ้านรู้กันหมดเลยว่าหนูเป็นเอดส์ เขาก็บอก หนูอยู่บ้านไม่ได้แล้ว ต้องไปอยู่ที่อื่น ...เขาบอกว่า ถ้าหนูอยู่ที่บ้าน แล้วทุกคนในบ้านจะอยู่ยังไง ชื่อเสียงวงศ์ตระกูลจะเป็นยังไง ญาติหนูก็เป็นครูบาอาจารย์ เป็นข้าราชการกันหมด เขาก็กลัว หนูก็เลยบอก ไม่เป็นไร เรารับผิดชอบชีวิตของเราเอง เพราะเราทำตัวเอง ให้หนูตายคนเดียวดีกว่าปล่อยให้คนที่บ้านตายทั้งเป็น (2/1: p14, 9-18)

Having Unwillingness to live

Having unwillingness to live was the state in which the participants lost their mental power to do anything to remain alive or had the desire to die. They did not take actions in taking care of themselves, but they instead intended to perform or actually performed actions that might harm their bodies. The action and interaction strategy of having unwillingness to live included not performing daily ordinary self-care, and entertaining a suicidal thought with or without attempted suicide.

Not performing daily ordinary self-care.

It refers to the participants' act of neglecting daily care necessary in maintaining the body's integrity. It happened in the first few days to a few months after the participants had an awareness of their HIV-infection. They neglected their personal hygiene, did not eat food, and lay about all day. These participants felt desperate, and some thought that they would die in a few days any way, so it was useless to do anything. The following participant's quotation provides a good example:

I didn't want to eat anything...I didn't want to have a meal...I felt like I must die after being infected. So I stayed like this then I could die automatically. (19/1: p2, 10-12)

เราไม่ยอมกินอะไร ไม่ยอมกินข้าว ... เรามีความรู้สึกว่ามันเป็นแล้วตาย เรานอนอย่างนี้ เดี๋ยวมันคงตายไปเอง (19/1: p2, 10-12)

Entertaining a suicidal thought

It refers to the participants' intention of self-destruction resulted from lack of a desire to live. They may or may not attempt suicide. The thoughts were a result of overwhelming distress and hopelessness as well as anticipated fear and anxiety about their future. Some felt shame or loss of dignity if others knew their HIV-status. So, they thought that if they were dead before sickness or symptoms appeared, no one would know about their infection. Some participants viewed living longer as more troublesome than 'dying.' Death would be the best way out of their situations. These participants concentrated on finding a suitable means to kill themselves, but not everyone actually attempted suicide. Some participants could not find the appropriate method, or dared not do it because they were afraid that the method might cause pain. Some were concerned about their families, so they

discontinued the suicidal thoughts. However, some tried to do it. The participants talked about the moment that they had suicidal tendencies as follows:

There was a period I kept being with myself, thinking of committing a suicide. Trying to figure how to die without leaving a disgusting dead body to the sight of people. Hanging was not the alternative as my mom would be too terrified... Swallowing rat poison would cause lots of foaming saliva on the corpse. I thought and thought of dying in many ways. If I had a gun, it would be just Bang! Fortunately, nobody had a gun in my house. If I had a gun, I would have shot myself already. (6/1 p7, 1-6)

มันมีช่วงหนึ่งที่เราก็กั๊กตัว ช่วงนั้นส่ะที่คิดฆ่าตัวตาย พยายามคิดด้วยว่าจะทำตายยังไงที่มันไม่ทุเรศ ไม่น่าเกลียดเกินไป เชือกผูกคอเดี๋ยวแม่มาเจอ แม่จะกลัว ... กินยาเบื่อหนู ก็น้ำลงน้ำลาย คิด คิด หลายทาง ถ้าตอนนั้นมีปืน ผมน่าจะยิงเดียว ดินะที่บ้านไม่มีใครมีปืน ถ้ามีปืนก็ยิงแล้ว มันชั่ว วาบจริงๆ (6/1 p7, 1-6)

During that time I was worried about what I could do if my symptom showed... Could my parents accept this? I became burden on others ...so, I thought I'd better find a way to end my life. The others wouldn't know that I was infected... When thinking of drinking poison, I was scared of the torment. Jumping in front of an oncoming car would be difficult if I didn't die and became disabled. When I saw a TV drama in which a star took sleeping pills to commit suicide and then I planned to deceive the physician that I was insomnia. I asked him for some sleeping pills and gained about 20 pills. The physician said I should take them before bedtime, so I took all of them. (4/1: p3, 14-27)

ตอนนั้นเป็นกังวลว่าถ้าตัวเองแสดงอาการแล้วจะทำยังไง ... พ่อแม่จะรับได้หรือเปล่า ตัวเองต้องเป็นภาระกับคนอื่นอีก ... เลยคิดว่า น่าจะหาวิธีจบๆมันไป คนเขาจะได้ไม่รู้เราคิดเชื้ ... คิดจะดื่มยาพิษก็กลัวทรมาน จะกระโดดให้รถชน เกิดไม่ตาย พิกลพิการก็ยุ่ง เป็นคนจี้กั๊ก พอดูทีวีไป เห็นนางเอกกินยานอนหลับฆ่าตัวตาย แล้วหลับไปเลย ก็คิดแผนเลยว่าจะไปหลอกคลินิกกว่าเรานอนไม่หลับ จะไปหลอกเอายานอนหลับเขามา เขาก็ให้มากินประมาณ 20 เม็ด เขาให้กินก่อนนอน กินเข้าไปหมดเลย (4/1: p3, 14-27)

Intervening conditions

Some participants passed the flight stage within a few days, whereas others took a longer time--a few weeks or a few months. In the cases of participants whose family knew their HIV status, some were rejected, while the others were not. Some participants actually attempted suicide while, others only thought about suicide. On the other hand, some participants had no idea about suicide. The intervening conditions that played important roles on these differences were the healthcare system and family system. The conditions of the healthcare system included the setting of the health center that detected the participants' HIV infection, the means of presenting the result of HIV blood test, and discrimination in providing healthcare. The conditions of

the family system were the relationships among family members and the participants' role in the family.

Health center setting

The participants who lived in a rural area and had HIV test at local hospitals thought that people in their communities either had already known their HIV status or would know it soon. In any small rural village in Thailand, everyone including health personnel knows each other. Consequently, these participants did not trust that their HIV test results would be kept confidential. They were in fear of being despised and did not dare to meet people in the village. This was clearly stated in one female participant's account:

Firstly, I was afraid that they would reject me ... because provincial society was too close-knitted. When the hospital employees knew it, they gossiped. Some who worked in the hospital were villagers (of my village). So, they talked and it became known to everyone. (20/1: p2, 8-11)

ที่แรกกลัวเค้าจะรังเกียจ ... เพราะว่าสังคมจังหวัด...มันแคบ พอที่โรงพยาบาลรู้ เค้าก็คุยต่อๆ พวกที่ทำงานโรงพยาบาลเป็นคนที่บ้านก็มี เค้าก็คุยรู้ต่อๆมา (20/1: p2, 8-11)

She explained what she had learned from other HIV-infected people as follows:

Doctors and nurses hardly kept patients' secrets. There was one whose relatives didn't know that he was infected (HIV positive). But when he was staying in the hospital, they knew because of the nurses' gossip. In the province...everyone knew those who had been infected. It could not be concealed if one had a check-up at the hospital. (20/1: p4, 1-5)

พวกแพทย์ พยาบาล ไม่ค่อยปกปิดความลับของผู้ป่วย มีคนหนึ่งญาติพี่น้องเค้าไม่รู้ว่เค้าเป็น (HIV positive) แต่พอมานอนโรงพยาบาลรู้ เพราะว่าพยาบาลกระซิบกระซาบกัน ที่จังหวัด...ใครเป็นรู้เลยไม่ต้องปิดบัง ถ้าได้เข้าไปตรวจในโรงพยาบาล (20/1: p4, 1-5)

Those who had their blood test done at a hospital in a big city or in the city far from their home or community were not afraid or anxious that their HIV status would be revealed to the community. Nevertheless, they were afraid and anxious that the others would know if the symptoms of AIDS appeared.

The means of presenting the result of HIV blood test

The ways each health center informed patients about the HIV blood test result were different. They were different in the information given and the recipient of the information. Some participants were informed of the result without any additional information. Some centers presented the diagnosis to the participants

with only the information that they would live for approximately two to three years. Some places presented the blood test result together with individual counseling.

The participants who did not receive any information or counseling when learning about their HIV infection misunderstood that they would get worse and die in a few days. The misconception occurred because they had seen from the media that AIDS patients must die. These participants felt fearful and were afraid that those who met them would know about their HIV infection. They stayed in their rooms and did not dare to meet anyone. They also neglected themselves and decided to passively wait to die.

Some participants received information and counseling when they got the blood test result. Some received the information when they had the second blood test. Examples of the information and advice they gained are as follows: There were a lot of HIV infected persons like them, so they were not alone; The infection would not make them sick or die suddenly; They could live for years without any symptom if they took good care of their health; and Other people would not know they were infected unless they informed them. Additionally, they were informed that they could live with others because it was not easy to get the infection. They were also given knowledge and information about how the disease could spread, how to care of themselves and health service center or other agencies where they could ask for help. Unfortunately, receiving information, advice, and suggestion while getting the blood test result did not make anything better because during that time the participants were too shocked, alarmed, and confused to take in the information. However, after they were calmed down, the information would help them get rid of some unnecessary fear and anxiety. They would not suffer under the misconception that they would die in a few days, and their fear about spreading the disease would also be reduced. These participants, thus, continued to live with their family or friend by concealing their infection, feeling relief that they would not infect others. The following participants' quotations reflected the differences made by the information given by the health centers while receiving the HIV blood test result:

The doctor didn't say anything but directly told me that I was AIDS infected. ...I just confused...but I knew I must die as I'd seen from posters that all AIDS patients would die. I thought that within the next three days I would certainly die. Didn't know what to do. And they didn't give me any advice. (3/1: p1, 7-11)

หมอเขาก็ไม่ได้พูดอะไร ก็บอกเลยว่าคุณติดเชื้อเอดส์ ... กังง แต่รู้ว่าจะต้องตาย เพราะเคยเห็นไปสเตอร์ว่า เอดส์เป็นแล้วตาย คิดว่าอีก 3 วันต้องตายแน่ๆ ก็ไม่รู้จะทำอะไร แล้วเขาก็ไม่ได้ให้คำแนะนำอะไร (3/1: p1, 7-11)

Before telling me about the blood test, she asked me to go to a counseling room. She let me sit for a while. There was a book about AIDS. So I opened and read it...I was at risk too...After a moment, a nurse came in and asked about my job...my family. ... Then she said, "I'll tell you something. Don't panic. You have AIDS. But you don't have to worry. You will live for a long time if you take care of your health, rest adequately, eat full five-group nutritious food, exercise, do not worry, and go to see the doctor when you feel sick." (15/1: p1, 12 – p2, 1)

ก่อนจะบอกผล เขาให้ผมเข้าไปในห้องให้คำปรึกษา เขาปล่อยผมนั่งซักพักนึง แล้วก็มีหนังสือเรื่องโรคเอดส์ ผมก็เปิด เปิด ... เอ๊ะเราก็เสี่ยงเหมือนกัน ... ซักพักนึง พยาบาลก็มาคุย ว่า คุณทำงานอะไร ... ทางบ้านเป็นยังไง ... ตอนหลังเขาบอกว่า ถ้าจะบอกอะไรให้ คุณอย่าตกใจนะ คุณติดเชื้อเอดส์ แต่คุณไม่ต้องกลัวหรอก คุณยังอยู่ได้อีกนาน ถ้าคุณดูแลสุขภาพ พักผ่อนให้เพียงพอ กินอาหารให้ครบ 5 หมู่ ออกกำลังกาย ทำจิตใจอย่าเครียด และหมั่นไปหาหมอตอนไม่สบาย (15/1: p1, 12 – p2, 1)

Another intervening condition in the flight stage concerned who was informed of the infection result. Some participants were personally informed. These participants usually concealed their infection. In some cases, according to the Act 1985 mentioned above, healthcare providers declared the participants' HIV status to the community. In other cases, healthcare providers revealed the diagnosis to someone in the participants' family during hospitalization. For example, a 30-year-old female participant had known from the blood test in the recruitment process of a company that she had the virus since 1991. At first, she concealed her infection from everyone. She attempted suicide and fainted, so she was sent to the hospital. Her infection was then disclosed to all of her family members as shown in her statement:

She took me to the hospital. The nurse told my elder sister that...I was AIDS infected. So everyone knew. (2/1:p14, 8-10)
เขาพาหนูส่งโรงพยาบาล พยาบาลเขาบอกพี่สาวว่า...น้องสาวเป็นเอดส์ ที่นี้รู้กันหมดเลย (2/1: p14, 8-10)

Another participant, a 35-year-old man, learned that he had the virus ten years before. He was an intravenous drug user and intended to quit the drug. When he applied to participate in a drug rehabilitation program, he had HIV blood test. He described how his blood test result was disclosed at that time:

During that time, there was no pre-test and post-test counseling service provided for blood test result. Not at all. The doctor just said it right to my sister. She then

ran to me with tears. They made a phone call to ...(name of the place)...for my blood test result. I was standing right next to my sister when the nurse turned to her to tell her the fact after she got the result over the phone. (1/1: p1, 11-18)

การบอกผลเลือดในตอนนั้นก็ไม่มี pre-test (counseling) ไม่มี post-test (counseling) อะไรหมอก็ยังไปบอกกับพี่สาวผม พี่สาวก็วิ่งมาร้องไห้ ตอนที่เขาโทรไปเช็คผลเลือด เขาก็เช็คกันทางโทรศัพท์ เขาส่งผลเลือดของผมไปที่... แล้วทางนั้นเขาบอกผลเลือดทางโทรศัพท์ พยาบาลที่สถานพยาบาลเขาก็บอกพี่สาวผม ผมก็ยืนอยู่ตรงนั้นแหละ (1/1: p1, 11-18)

As a result of disclosure of the participants' HIV status to the community, they and their families were rejected. These participants were excluded from the community in which they had lived all their lives. Families who knew their infection reacted differently. Some HIV-infected people received more support from the families, some were forced to separate their living area in the house and to avoid touching and sharing meals because their families were afraid of contracting the virus, while others were abandoned with little or no help or support. What the results would be like seemed to depend on the background of the family and the relationships among family members.

Discrimination in providing healthcare

Healthcare personnel were frightened when they discovered HIV-infected people. They provided care to HIV-infected patients in a fearful and unwilling manner. Moreover, some health centers refused to give treatment, surgery, or antenatal care to HIV-infected people.

A 27-year-old male participant had a severe motorcycle accident ten years ago. And at that time he knew his HIV-infection. The physician firstly told his mother that he was HIV-infected and that he had only two years left to live. The physician refused to perform the needed operation. His mother told him when he got better and gave him moral support. Now, some deformity on his pelvis and his posture especially when walking could be seen clearly. He described what happened to him as follows:

At that time, I was traumatically hurt, physically and emotionally... The doctor refused to give me an operation. He just offered the bone traction and let it connect by itself ...but no operation. So I had to stay still and wait till I recovered. It seemed like they did nothing. I got an accident in another province and doctors of the hospital there said I must have an operation...I was transferred to a hospital in Bangkok. But the doctors in Bangkok refused to give me the operation...The doctor told my mom since I was first admitted that there would be no operation because of (HIV) infection. But my mother didn't inform me

because I could not accept this condition... At that time I only thought about what I could do next in case I became disabled. (12/2: p2, 7-17)

ตอนนั้น เป็นความรู้สึกที่แย่มาก ... เราถูกปฏิเสธการผ่าตัด ซึ่งหมอให้ดึงกระดูก ใช้วิธีการดึงกระดูก แล้วให้กระดูกติดกันเอง ... แต่เขาไม่ผ่าตัด ก็คือผมต้องนอนอยู่เฉยๆ รอให้กระดูกติด ซึ่งมันเหมือนกับไม่ได้ทำอะไรเลย ผมประสบอุบัติเหตุที่ต่างจังหวัดหมอที่โรงพยาบาลต่างจังหวัดเขาบอกว่าต้องผ่าตัด ... ผมย้ายเข้าโรงพยาบาลในกรุงเทพ แล้วหมอในกรุงเทพเขาไม่ผ่าตัด ... หมอบอกแม่ตั้งแต่ต้นว่าเขาไม่ผ่าตัดนะ เพราะว่าติดเชื้อ (HIV) แต่คุณแม่ยังไม่บอกผม เพราะว่าผมยังรับภาวะตรงนี้ได้ ... ตอนนั้นผมคิดอย่างเดียว คือ ถ้าเราพิการเราจะทำอย่างไร (12/2: p2, 7-17)

Another female participant was pregnant ten years before. She went to an antenatal care clinic of a private hospital and had an HIV blood test. That hospital refused to give her antenatal care because she was HIV-positive as indicated in her statement:

At that time I was about 3-month pregnant. I went to sign up for antenatal care. Firstly they asked me for blood test, but they didn't tell me they wanted to test for this infection. They just told me that the doctor wanted to test my blood. After the blood test ...about a week...they didn't say anything but directly told me that I was AIDS infected and they said they couldn't give antenatal care to me there. (3/1: p1, 3-8)

ตอนนั้นท้องประมาณ 3 เดือน หนูไปฝากท้อง ครั้งแรกเขาบอกว่าเขาขอเจาะเลือด แต่เขาไม่ได้บอกว่าเขาจะเจาะหาเชื้อตัวนี้ คือแค่บอกว่าหมอจะเจาะเลือดคุณ พอหลังจากเจาะ ... อีกอาทิตย์นึง ... หมอเขาก็ไม่ได้พูดอะไร ก็บอกเลยว่าคุณติดเชื้อเอดส์ ที่นี้ไม่รับฝากท้องให้ (3/1: p1, 3-8)

Relationships among family members

In this study, the close and warm relationship among family members was very important as it could reduce the suffering of the participants and protect them. In the case where families knew that the participants were HIV-infected and there was a good relationship, the participants would quickly pass the stage of flight within a few days. They promptly gained support, care, and understanding from their family. They were also able to express their frustration. They would be relieved and feel better that their family accepted their infection. In addition, they would feel they were worthy for their family. The persons who were most important to them were usually their father or mother. It is worth noting that even though these well-supported participants might have an idea to commit suicide, it lasted only for a short period and they did not actually attempt to do so.

One female participant who contracted HIV from her husband lived with her own family. Her family also knew her HIV status from the hospital. She felt so much relieved when she learned that everybody in her family accepted her, as she stated:

When I came back from the hospital. ... I stayed in the room and then cried alone. I did not dare to come out. I did not eat. I felt bored myself. I kept myself in the room. My elder sister came to comfort me. She said she had known it. It was not necessary to conceal it from her because the hospital official had informed her already. She said it was useless to be sorry. ... After she talked to me, mom also talked to me, so I felt better. I'd just be scared they might object to my husband... Thus, I was worried so much. When my husband came back, they treated him as usual like nothing happened. I asked mom whether she felt disgusted. She said no. those who had this disease could live long. She asked me to look after my health. She calmed me everything. I felt relieved that, Yes, I had both mom and dad. Both of them didn't reject me, so I was not afraid of anyone. (20/2: p2, 14 – p3, 3)

ตอนที่หนูกลับมาจากโรงพยาบาล ... หนูเก็บตัวอยู่ในห้อง แล้วหนูก็ร้องไห้คนเดียว ไม่กล้าออกมา ไม่ทานอาหาร เบื่อตัวเอง เก็บตัวอยู่ในห้อง พี่สาวเข้าไปปลอบ เค้านบอกว่า เค้านรู้ ไม่ต้องปิดบังเค้า เพราะโรงพยาบาลเรียกเค้าไปคุยแล้ว เค้านบอกว่าไม่ต้องเสียใจ ... พอพี่สาวพูดมา แล้วแม่ก็เข้ามาพูดอีกก็เลยสบายใจ เราก็กลัวเค้าจะรังเกียจแฟน...ก็เลยคิดมาก พอแฟนเค้ากลับมา เค้าก็ปกติกับแฟนหนู เหมือนไม่มีอะไรเกิดขึ้น หนูก็ถามแม่ว่า แม่รังเกียจมั๊ย เค้านบอกว่าไม่รังเกียจ โรคนี้มันอยู่ได้นานนะ ให้รักษาสุขภาพ เค้านปลอบหนูทุกอย่าง หนูก็เลยโล่งว่า เออมีทั้งแม่ทั้งพ่อ ไม่รังเกียจทั้งสองคน ก็ไม่ต้องไปกลัวใครแล้ว (20/2: p2, 14 - p3, 3)

In this case everything became all right since her family accepted her, did not feel disgusting that it was, and supported her. This participant had no suicidal idea and could rapidly get over her distressed feeling.

To live with the warm and close relationship in the family, whether their family knew that the participants were infected or not, could help prevent the self-immolation of the participants. Since the participants would be concerned about their family members when they intended to hurt themselves. Furthermore, their family would take care of them. The warm and close relationship in the family would also be an environment that facilitated the disclosure of the participants' HIV status to the family. The disclosure to the family when their family understood and was supportive was an essential turning point from the stage of flight to the next stage, in which the participants turned to face the problem. It made the participants feel contented and more relieved, and they could find the meaning in their lives.

The participants' role in the family

The participants who perform the role of the family's breadwinner, especially those who had young children, could undergo through the stage of flight rapidly. They would feel depressed and desperate for a few days. The responsibility of childcare or parental care would make them strong and think that they must do the

best for the family in the time that they had left. They, thus, could overcome sadness, sorrowfulness, and desperation more quickly.

Consequences

The consequences of the participants' action and interaction strategies in the flight stage were suffering and encountering the difficulties in living. Keeping their HIV status a secret and avoiding social contact made them suffer from loneliness and harassment. They could not ventilate their feelings with others or consult others about their problems or their situations, so no one understood them. The participants expressed their feelings at the time that they hid their HIV status from everyone as follows:

At that time nobody knew. I was so suppressed, I didn't know whom I could talk to ... Wherever I visited, I found people talk about AIDS... At that time I was very chagrined. I wanted to talk to somebody but there was nobody to talk to. (4/1: p4, 7-15)

ตอนนั้นไม่มีใครรู้เรื่องเลย เราก็อึดอัดมากเลย ไม่รู้จะคุยกับใคร ... ไปไหนเจอแต่คนคุยกันแต่เรื่องเอดส์ ... ช่วงนั้นใจเสียมากเลย อยากจะคุยกับใคร ไม่มีใครให้คุยเลย (4/1: p4, 7-15)

I used to enjoy night life, but now I must be reserved... be without friends. It was very suffering because I used to be so happy among cheerful friends, and then I had to separate myself to stay alone. (16/2: p2, 15-19)

จากโสดเล่นในชีวิตกลางคืน แล้วมันกลายเป็นว่าต้องเก็บตัว ไม่มีเพื่อนเลย มันทรมานมากกับการที่อยู่ดีๆ อยู่ในวงเพื่อนฝูงที่เฮฮา กัน แล้วต้องแยกตัวออกมาอยู่คนเดียว (16/2: p2, 15-19)

The participants also suffered with the distressed feelings and unpleasant symptoms such as headache and insomnia because of their circuitous thoughts of their fear and anxiety. Some participants had to endure painful symptoms from their suicidal attempt. Moreover, the participants who were rejected by families and communities and left their home and community had to encounter the difficulties in living.

In summary, the participants in the flight stage perceived HIV infection or AIDS as a terrible disease: incurable, sooner death, and disgusting. They were overwhelmed with distressed feelings including sadness, hopelessness, fear, and anxiety. Their perception was still the same at the end of this stage. The participants in this stage could be divided into two groups. Group one included the participants who did not disclosed their infection to anyone. Most of them kept their HIV status a secret and avoided social contact. Few participants, who lived with family under a

warm and close relationship, told someone they could confide in their family promptly. Group two included the participants whose infection was disclosed to the family, and some to the community, too. These participants had to leave their home and community except in the cases that their HIV status was known only to the family with acceptance. Several of them in both groups were unwilling to live. Some participants attempted suicide, while others did not. Consequently, they were suffering, and some who left their home, had to encounter the difficulties in living alone.

Stage 2: Pulling Oneself Together to Fight

The second stage, pulling oneself together to fight, was like a turning point of the participants from flight to fighting. In this stage, the participants made themselves different, leaving a state of despair and entering into a ready state to manage their lives. Some changed themselves from not willing to live to having some purposes in living. It was close to and sometimes even overlapped, the flight stage. The casual conditions that led them to undergo this stage were suffering and the realization of sooner death. The contextual conditions in this stage were the same as those the flight stage.

Causal conditions: suffering and realization of sooner death

The participants' suffering had occurred since the previous stage. They suffered with the distressed feelings and unpleasant symptoms such as headache and insomnia because of their circuitous thoughts caused by fear and anxiety. They also suffered from loneliness, and some participants had painful symptoms from their suicidal attempt. They could not express their feelings and share their problems with anyone, and other people around them did not understand what was happening to them either. The participants could no longer stand these states, so they took some actions to relieve sufferings.

Another important condition was the realization of sooner death. All of the participants perceived that HIV-infection or AIDS could not be cured. Most of them realized that they were going to die within a few years. It made them see and think

everything much differently, and it also led them to come to terms (*tham jai*) and search for the meaning in living.

Action and interaction strategies

The stage of pulling oneself together to fight involved the strategies of seeking help, overcoming the distressed feelings, and finding the meaning in living. These action and interaction strategies seemed to be developed simultaneously and facilitate each other.

Seeking help

The participants were suffering with the distressed feelings, so they needed help from someone or something. They needed someone, whom they trusted, to listen to everything they needed to say or do whatever they could to make them feel better and relieved. They might seek help from someone in their family, healthcare providers, friends, and the respected spiritual matters. They might also seek help from only one source or many sources, and some sources might lead to another one.

Seeking help from family

At this time, the participants needed help from someone around them. The participants who had hidden their HIV status and lived with their family decided to disclose it to someone they could confide in in the family. Some participants disclosed it unintentionally because of the utterly repressed feeling. Some participants disclosed it a few days or a few weeks after they had known the diagnosis, but few participants did it immediately. The participants could express their distressed feelings to the family members and got support from them. The helpful manners of the family included accepting, comforting, encouraging, seeking healthcare for the participants, giving helpful information, and giving advice.

For example, a male participant had known his diagnosis of HIV-infection for two weeks before he decided to disclose his infection to his mother and then to his siblings as he stated in the following quotation:

I decided to tell my Mom that ... I was AIDS infected. Mom is Chinese. She didn't know about AIDS. She said I shouldn't fear it. She will take me to join a possessed ritual and then I would become well. So, I, umm...felt better a bit. Then I started telling my brother and sister... each of them wasn't afraid of me. (15/1: p2, 14-22)

ผมตัดสินใจบอกแม่ว่า ... ผมเป็นเอดส์ แม่เป็นคนจีน เข้าไม่รู้หรือเรื่องเอดส์ แม่บอกว่า ไม่ต้องกลัวหรือ เดี่ยวเค้าพาไปหาเจ้าเข้าทรงก็หาย เราก็ เออ...มีกำลังใจขึ้นมา

หน้อย แล้วก็ค่อยๆบอกพี่ บอกน้อง ... แต่ละคนไม่มีความรู้สึกกลัวเลย (15/1: p2, 16-22)

His family's entire members responded to the news he told with acceptance, and they encouraged him as shown in his following statement:

They were alarmed. Some didn't know what AIDS symptoms would be like. They just knew patients must become thin and die... They saw I was still fine... They said I was not infected...I would be O.K. ...When everyone in the family accepted me, I felt relieved...very released. (15/1: p18, 3-9)

เค้าก็รู้สึกตกใจ บางคนก็ไม่ว่าเอดส์เป็นยังไง เค้ารู้อย่างเดียวว่ามันต้องพอม มันต้องตาย ... เค้าเห็นเราไม่เป็นไร ... ทุกคนก็บอกไม่เป็นหรอก ไม่เป็นหรอก ... พอทุกคนในบ้านรับได้ เราก็สบายใจ โลงเลยแหละ (15/1: p18, 3-9)

It resulted in a huge relief for the participants when their family knew that they had HIV and still accepted them. Another male participant felt utterly repressed and disclosed his HIV infection to his family unintentionally as indicated in his statement:

I couldn't tell anyone... I also felt uneasy... and at that time I revealed it without hesitation. I didn't mean, but it just came out. (6/2: p2, 31 – p3, 2)

เราบอกใครไม่ได้ ... เราก็อึดอัด ... แล้วตอนนั้นมันหลุดออกมาเลย โดยไม่ได้คิดเลยนะว่าจะบอกหรือไม่บอก (6/2: p2, 31 – p3, 2)

His family accepted and always encouraged him as he said:

They were not disgusted with me. They always gave me encouragement. (6/1: p4, 32 – p5, 1)

เขาไม่ได้รังเกียจ เขาพูดให้กำลังใจตลอด (6/1: p4, 32 – p5, 1)

Two participants told their diagnosis to the family immediately with no doubt. They needed help and advice about what to do next, and they were sure that their family could help them in some way. One male participant told his parents right after the diagnosis that he had HIV:

When I first knew I was infected, I told my parents... It was only known among family members...brother, sister, Dad, and Mom: only four of them knew. Just among family members. We were not open about this because we knew others would feel disgusted. (9/1: p5, 8-22)

เริ่มแรกก็รู้ว่าติดเชื้อก็บอกพ่อแม่ ... รู้เฉพาะในครอบครัวผม ... พี่ชาย พี่สาว พ่อ แม่ รู้กันแค่นั้น รู้กันภายในบ้าน ไม่ได้เปิดเผย เพราะรู้ว่าคนอื่นเขารังเกียจหน่อยๆเลย (9/1: p5, 8-22)

In this case, his father was a physician. After telling his family, they comforted him, sought healthcare for him, and his father gave him encouragement, helpful information, and advice. He expressed how his parents supported him as follows:

My parents tried to soothe me. “You’re O.K. boy. Take care of yourself.” Mom found medicine for me and tried to search for herbal medicine from many temples for me. ...My Dad brought me a book, very big book. It was about medicine, about HIV. Dad is a physician. He brought me this book to have a look. HIV-infection was nothing, he said. I saw the pictures about HIV symptoms. (9/1: p5, 32 – p6, 3)

พ่อแม่เขาพยายามปลอบใจ ‘ไม่เป็นไรหรอกลูก พยายามรักษาตัว’ แม่เขาพยายามให้กิน พยายามสรรหาตามวัดอะไรต่างๆ มาให้ ... พ่อผมเอาหนังสือมาให้ดู หนังสือเล่มใหญ่ หนังสือเกี่ยวกับแพทย์ เกี่ยวกับโรค HIV พ่อเป็นหมอ เอาหนังสือมาให้ดู ‘ไอ้โรคนี้ มันไม่มีอะไรหรอก เอารูปมาให้ดู ลักษณะอาการมันเป็นอย่างนี้’ (9/1: p5, 24 – p6, 3)

His father explained the nature of the disease to him and made some changes in his perception of the disease. His father also encouraged him and advised on how to care for himself as in the following account:

Daddy told me that people died because of the opportunistic disease. They didn’t die from HIV... So, I’ll fight. I won’t surrender. (9/1: p4, 25-28) ...Dad said it was nothing. I shouldn’t be afraid of it. Let’s fight against it. Shouldn’t fear it. I should try to take care of my health. Now it’s nothing. Tried to be brave. It’s enough. And ate nutritious food. Did exercise... stopped drinking alcohol and smoking... Didn’t sleep late... And tried not to receive more virus. As a result, it would be nothing. (9/1: p6, 5-13)

คุณพ่อบอกผมว่า คนตาย ตายเพราะโรคแทรก ไม่ได้ตายเพราะ HIV ไม่ได้ตายเพราะติดเชื้อตัวนี้ ... ผมก็เลยสู้ ไปขอม้ำมันทำไม (9/1: p4, 25-28) ... พ่อบอกไม่เป็นไรหรอก ไม่ต้องไปกลัวมัน สู้กับมัน ไม่ต้องกลัวมัน พยายามรักษาสุขภาพ ตอนนี้ไม่มีอะไรหรอก พยายามทำจิตใจให้เข้มแข็ง พอแล้ว แล้วก็กินอาหารที่มีประโยชน์ ออกกำลังกาย ... พยายามอย่ากินเหล้า สูบบุหรี่ ... อย่านอนดึกมาก ... แล้วพยายามอย่าไปรับเชื้อเพิ่ม มันก็ไม่มีอะไร (9/1: p6, 5-13)

Another participant concealed his HIV-infection from his parents because he did not want to worry them. He revealed it instantly to his older sister who was a nurse, and she helped him seek healthcare. He said:

After I had been informed about the blood test result, I told my sister as I needed a suggestion... I only told my sister because she was close to me. We always talked and shared...so I asked for suggestion about kinds of medicine. I didn’t know where I could find medicine. I asked her. Then she asked doctors where to find them. (10/2: p2, 26 – p3, 3)

ตอนที่ทราบผลเลือดผมบอกพี่สาวเลย มันต้องปรึกษา ... บอกพี่สาวคนเดียว เพราะว่าพี่สาวกับผมติดกัน มีอะไรระบายความในใจกันได้ ... ก็ปรึกษาพี่ว่า ที่ไหนมียาอะไร ไม่รู้ว่ายาที่ไหนมี ต้องปรึกษาพี่ พี่ก็ต้องไปถามหมอว่า ที่ไหนมี (10/2: p2, 26 – p3, 3)

Seeking help from healthcare providers

Some participants especially those who did not live with their family firstly sought help from healthcare providers by themselves. Some participants sought it with some support from their family. And in some cases, someone in their

family did it for them. The helpful manners of healthcare providers included giving helpful information, providing healthcare, giving counseling, initiating and introducing the participants to a group of HIV-infected people, and co-operating with other organizations to give further support.

Some participants **did not** live with their family and concealed their HIV-infection from everyone. They needed someone who they could vent their feelings or consult their problems. Thus, these people returned to the healthcare providers, who gave counsel to them at the time they were informed of their HIV infection. Some participants stopped living alone, and they were taken to the health center where they had been advised when they first learned the diagnosis. These participants gained more information and more advice. Moreover, healthcare providers introduced them to a group of HIV-infected people or persuaded them to join a forming group of HIV-infected people. This brought a big change to them. They had friends who had the same fate, so they did not feel lonely anymore. And this was also a great opportunity for them to rediscover themselves and their lives that they were more valuable later. For example, a female participant said the following:

At that time, nobody knew [that I was HIV infected], so I felt very suffocated. Didn't know whom I can talk to... Wanted to talk to somebody, but nobody to talk to. So, I turned to see the former counselor who used to give me advice. He suggested I should go to the club... At that time, it wasn't a real club yet. They'd just started forming a group ... He said...Hey! There was a place where people on the same boat got together. After spending sometimes with them, I felt better. (4/1: p4, 7-28)

ตอนนั้นไม่มีใครรู้เรื่อง (ที่ตนติดเชื้อ HIV) เลย เราก็อึดอัดมากเลย ไม่รู้จะคุยกับใคร ...อยากจะคุยกับใคร ไม่มีใครให้คุย เลยกลับไปหาพี่คนเก่าที่เขาเคยให้คำปรึกษาเรา เขาก็แนะเราให้ไปที่ชมรม... ตอนนั้นยังไม่เป็นชมรม ตอนนั้นเขาเริ่มรวมกลุ่มกัน ... เขาบอก นี่นะมีที่เป็นเหมือนเรา เขารวมกลุ่มกัน มาคุยกัน ... พอได้ไปคุยกับชมรม... ก็ดีขึ้น (4/1: p4, 7-28)

Another 52-year-old single male participant had lived alone for a long time. When he was a child, his parents separated, and both of them had a new family. His grandparents took care of him. He had worked at nightclubs, bars, or cafeterias. When he knew that he had HIV infection, he did not meet friends nor go to work. He sometimes thought about suicide, but finally he decided to go to the health center where he was received advice from a counselor on the day when he knew his HIV blood test. He saw many AIDS patients with typical symptoms that made him feel worse. However, he had a chance to join a group that consisted of HIV-infected

people and some healthcare providers. That was the time that he began to have a feeling of hope. The following is his statement describing his story:

Previously my brain was madly stressed... I thought of jumping from the building... I had rented a room on the 4th floor... just looked down and thought. Suppose that I jumped from the 4th floor, I would surely survive if my head didn't knock the floor and my neck wasn't broken. If I directly attacked the floor, at most my legs would be broken. I couldn't walk, so what can I do then? I, thus, decided not to commit suicide. I came to [a hospital].... Till I joined a group and got to know more ... Then, they only had Wednesday treatment... I thus waited only for Wednesday so that I could get together with people with similar condition and release everything... Unlike when I was with other friends...whom I would never let them know anything. I was afraid that they would know [my infection]...My hope rested on the day, Wednesday. I'd never miss it. (16/1: p8, 19-28)

ตอนนั้นสมองจะเครียดมากเลย ... ผมคิดจะกระโดดตึก ... ผมเช่าอยู่ชั้นสี่ ก็มองลงมา ถ้าผมโดดลงมาชั้นสี่ ไม่ตายแน่ ถ้าหัวไม่ลง คอไม่หัก ถ้าลงไปตรงๆ อย่างเก่ง ขาหัก เดินไม่ได้ ทำไงดี ก็เลยตัดสินใจว่าอย่าดีกว่า ก็เลยมาที่[โรงพยาบาลแห่งหนึ่ง] ... จนกระทั่งมาทำกลุ่ม เริ่มรู้อะไรมากขึ้น ... แค่นี้ก็ปรึกษาเฉพาะวันพุธนะสัปดาห์ก่อน ... จะรอวันพุธวันเดียว เพื่อที่จะได้มาพบเพื่อน เพื่อที่จะได้มาปล่อยทุกข์ทุกอย่างกับเพื่อนเรา กับเพื่อนเก่าๆก็บอกเค้าไม่ได้ คบกับเค้าก็มีความรู้สึกที่ว่ากลัวเค้าจะรู้ ... ความหวังของผมวันเดียว ก็วันพุธ ผมจะไม่เคยขาดเลยซักวันเดียว (16/1: p8, 19-28)

He also had an opportunity to talk with a nurse who worked as a counselor and joined the group as well. She gave him counseling which made him see how to live as an HIV-infected person. He said the following:

I've found the light. It means I'd talked to a nurse...private talk. After talking, I felt that there were so many things that I could do to adjust my status on earth. Since being infected person, I had changed this thought to be [power for] working. (16/1: p7, 5-8)

ผมได้พบแสงสว่าง คือ ได้คุยกับพี่ [พยาบาลผู้หนึ่ง]...เป็นการส่วนตัว พอคุยแล้วเรารู้สึกว่า โลกนี้ยังมีอะไรอีกหลายๆอย่างที่สามารปรับเปลี่ยนบทบาทของเราได้ จากการที่เราเป็นผู้ติดเชื้อ เราเอาใจความที่เราคิดเชื่อเนี่ย เอามาทำเป็นงานซะ (16/1: p7, 5-8)

Some participants received helpful information that they had not known before. A 35-year-old male participant received the information from a physician that changed his perception and his risk behaviors. He shared what the physician said to him:

You can live for a long time if you change your behavior and stop receiving more AIDS virus. Sleep and have enough rest. Have meals with full five groups of nutritions. Frequently exercise. Stop drinking alcohol and smoking. Make your mind relaxed. (19/1: p2, 20-22)

คุณยังมีชีวิตอยู่ได้อีกนานนะ ถ้าคุณเปลี่ยนพฤติกรรม แล้วคุณอย่ารับเชื้อเพิ่มอีก นอนหลับพักผ่อน ให้เพียงพอ ทานอาหารให้ครบหลัก 5 หมู่ ออกกำลังกายสม่ำเสมอ ไม่กินเหล้า ไม่สูบบุหรี่ ทำจิตใจ ให้สบาย (19/1: p2, 20-22)

With the physician's word, "You might live long," he changed his behaviors. He took care of himself to live as long as it could be.

A female participant contracted HIV from her husband. She knew her infection from an antenatal clinic of a hospital when she was pregnant. The hospital refused to give antenatal care to her and did not give her any information about the disease. She was so fearful and thought that she must die in a few days. After a few days had passed, she did not get sick or die. Her husband encouraged her and took her to seek antenatal care from other hospitals. She was afraid of being rejected again. But this time she received the valuable information and a pleasing healthcare. She was recruited into the project of the hospital caring for HIV-infected mothers and the babies. Then, she had a great hope and waited for her child's birth. She said the following:

The hospital staffs said it was not easy to die. I could live for many years if I took a good care of myself. My child might not be infected, too. Then I joined the project of the hospital. They would provide milk for the baby and also offered free-of-charge health check-up till the delivery, till my baby was one and a half years old. I felt released when I went to the hospital. It was because I knew that I had to take good care of health and avoid stress. Afterwards, my child would be born, and my child might not be infected. I had hope. I never missed the doctor's appointment. I always seen them and took best care of myself. (3/1: p4, 2-7)

เจ้าหน้าที่เขาบอกว่า ไม่ตายง่ายๆหรอก อยู่ได้อีกหลายปี ถ้ารักษาสุขภาพดีๆ ลูกอาจไม่ติดเชื้อก็ได้ แล้วหนูก็ได้เข้าโครงการของโรงพยาบาลที่ช่วยเรื่องนมลูก แล้วก็ตรวจสุขภาพให้ฟรีจนคลอด จนลูกขวบครึ่ง พอไปโรงพยาบาลหนูก็สบายใจ เพราะรู้ข้อมูลว่า ต้องดูแลรักษาสุขภาพให้ดี ไม่เครียด แล้วลูกก็ได้คลอด อาจไม่ติดเชื้อ หนูก็มีความหวัง ก็จะไม่มีการไหนที่หมอนัดแล้วหนูไม่ไป ก็จะไปทุกครั้ง แล้วหนูก็ดูแลตัวเองอย่างดีที่สุด (3/1: p4, 2-7)

Another helpful manner of health center was co-operating with other organizations to give further support to those who needed it. A poor female participant had a suicidal idea when she knew that she was HIV-infected. After she obtained some help -- the information about HIV/AIDS, advice, a medical care fee, a house, food, and occupation training from the organization that contacted with the hospital, she gave up the idea:

The doctor said I had AIDS ...so I told him that [I would] definitely commit suicide...He told me that it was hard to die though having AIDS infection. I could live for a long time just because of courage. Finally I saw the hospital's social welfare officials. So they brought me to the shelter [an organization, which offers help for sufferers.] (7/1: p1, 12-16)

หมอบอกว่าหนูติดเชื้อเอชไอวี ... ก็เลยบอกหมอว่า ฆ่าตัวตายแน่นอนเลย ... หมอก็บอกว่า ติดเชื้อเอชไอวีไม่ใช่ว่าตายง่ายนะ มันอยู่ได้ชั่วยาวนาน เพราะกำลังใจ กำลังใจเท่านั้นแหละ สุดท้ายไปหานักสังคมของโรงพยาบาล เขาก็เลยพาไปบ้านพักฯ [องค์กรที่ให้ความช่วยเหลือแก่ผู้ติดเชื้ออื่น] (7/1: p1, 12-16)

Seeking help from friends

The participants classified friends into two groups, non HIV-infected friends and HIV-infected friends. Non HIV-infected friends referred to people who were not infected with HIV and whom the participants used to be associated with in some way. They might be classmates or workmates of the participants, or they might have known each other through some activities. HIV-infected friends referred to people who were infected with HIV. Healthcare providers usually introduced these people to the participants. The participants defined HIV-infected friends as the ones, who had the same destiny as them; shared similar problems, concerns, and feelings; and also deeply understood them.

In those days, HIV-infected people hid themselves from the society. They did not tell their HIV status to other people. The groups of HIV-infected people had just begun to be formed informally in some hospitals by the initiation of healthcare providers, such as physicians, nurses, and social workers. The groups had not been well established, had no networks, and were not known to the society as they are these days. Thus, at that time (over ten years ago), it was difficult for HIV-infected people to directly access to HIV-infected groups or HIV-infected friends without some help from healthcare providers.

HIV-infected friends had important roles to move some participants from the stage of flight to the stage of pulling themselves together to fight, whereas non HIV-infected friends had no significant role and sometimes seemed to have negative effects on the participants. In the case that the HIV status of the participant was disclosed to the community, friends were fearful of contracting the virus and avoided being associated with him. Sometimes the reactions of friends increased stress to the participants or induced a suicidal idea. An example of the effect

of a non-HIV-infected friend's reaction was expressed in a homosexual male participant's statement as follows:

Previously I was lonely and got stressed... I talked to my friend. He was gay. I just told him to use a condom whenever having sex because now I had gotten AIDS... He replied that he would certainly commit suicide if he had it. He wouldn't live. He said like this. It made me feel more stressed. Instead of consoling me, he said he would certainly commit suicide if he'd gotten it. It was like a suggestion, like he wanted me to commit suicide. So, I thought...Umm, committing suicide... well. (15/1: p2, 6-29)

ตอนนั้นเราเหงา เราเครียด ... ไปคุยกับเพื่อน เพื่อนก็เป็นเกย์ ... ก็บอกเพื่อนว่า ถ้าจะเที่ยวก็ใส่ถุงยางนะ ตอนนี้เป็นเอดส์แล้วหละ ... เพื่อนก็บอกว่า ถ้าเค้าเป็น เค้าฆ่าตัวตายแน่เลย เค้าไม่อยู่หรอก เค้าพูดอย่างนี้กับเรา เราก็รู้สึกว่ามันยิ่งทำให้เราเครียด แทนที่เค้าจะปลอบใจเรา เค้ากลับพูดว่า ถ้าเค้าเป็น เค้าจะฆ่าตัวตาย ก็เหมือนว่า พูดทำนองว่า อยากให้เราไปฆ่าตัวตายดีกว่า เราก็คิด... เค้าฆ่าตัวตายก็ดี (15/1: p2, 6-29)

The helpful manners of HIV-infected friends and groups included listening to the problems, sharing problems and experiences with each others, caring, comforting, encouraging, and creating a sense of purpose in living. The participants who had an opportunity to meet HIV-infected friends reported that they felt much more relieved when they found other people who were the same. They regularly went to join the HIV-infected group. They vented their distressed feelings and shared their problems and experiences with the group. After they had known some HIV-infected friends, they had a social life as human beings again and did not feel lonely any longer. This is clearly reflected in one participant's following statement.

When I met friends who had gotten the same status, I felt like I was not alone on earth. There were those who were the same as myself... I felt I'd found my world. I was the one, too. It's hard to explain this kind of feeling while living among the same people... We are human and humans have their own society. When I was told that I was different or I was an alien, it was the most heartless emotion. Felt like I was alone among the crowd. But this time I knew that was wrong. There were lots of people who were the same as me. I felt like - Oh! I had gotten friends; I had gotten my own society. I was not lonely among people. (2/2: p2, 26 – p3, 11)

ตอนที่เจอเพื่อนที่เหมือนกัน มีความรู้สึกเหมือนว่า เราไม่ได้อยู่คนเดียวแล้วในโลก ยังมีคนที่เหมือนเรา ... เราารู้สึกเหมือนกับโลกของเรา เราก็คือคนคนหนึ่งที่อยู่ใน ณ ที่นี้เหมือนกัน แล้วก็อยู่ร่วมกันหลายๆคนที่เหมือนกัน มันบอกความรู้สึกแบบนี้ได้ยาก ... คนเรามันเป็นมนุษย์ มนุษย์มันก็มีสังคมของมัน ทีนี้พอเราถูกบอกว่าเราแตกต่าง แปลกแยก ความรู้สึกที่มันโหดร้ายที่สุด ก็คือว่า เราอยู่ท่ามกลางคนเยอะแยะ แต่เหมือนอยู่ตัวคนเดียว แต่ทีนี้พอเรารู้ว่ามันไม่ใช่เป็นแบบนั้น มันมีคนหลายคนที่เป็นเหมือนเรา มันรู้สึก อู้ย! เรามีเพื่อน มีสังคมแล้ว เราไม่ได้โดดเดี่ยว ท่ามกลางคนมากมาย (2/2: p2, 26 – p3, 11)

Seeking help from respected spiritual matter

Respected spiritual matters referred to the objects that participants paid respect to or the practices that were believed to bring good wishes. The respected spiritual matters were usually associated with religion. Most of the participants were Buddhists. These things might give them spiritual support. For example, a male participant described what he did after he had recently known that he was HIV-infection:

I was very depressed. I went to many temples and made a votive prayer, wishing I would recover. I prayed. I felt very unhappy, thought so much, and became insomnia because I didn't know how to deal with it... I thought about how I could live in the future since there was no medicine to cure this disease. I was just able to pray to Lord Buddha as much as I should do. (9/1: p2, 25-29)
 ผมรู้สึกใจมาก แล้วก็ไปบ่นตามวัดต่างๆ ขอให้หาย แล้วก็ไหว้พระ กลุ่มใจมากเลย คิดมาก นอนไม่ค่อยหลับ เพราะไม่รู้จะทำยังไง...ผมคิดมากกว่าอนาคตจะเป็นยังไง เพราะว่าโรคนี้มันไม่มียารักษา ก็ได้แต่สวดมนต์ ไหว้พระ ตามเรื่องตามราว (9/1: p2, 25-29)

Another male participant, with his mother, also sought help from their spiritually respected matters, and he somehow felt better:

Mom took me to see a monk. He told me that my destiny was threatened. He advised Mom to pray for me with the famous monk named Somdej Pra Buddhajan Dho Bhrommaransi. I should pray and offer him water in the morning. And then I should pray in order to drink it as a medicine. Therefore I usually followed his advice every morning. After waking up and washing my face, I prayed first and offered water to the monk. Then, my health became better. (19/1: p5, 15-20)
 แม่พาไปหาพระองค์หนึ่ง ท่านบอกว่าชะตาผมขาด ให้แม่ยกผมให้เป็นลูกของสมเด็จพระพุฒาจารย์โต พรหมรังสี แล้วให้สวดมนต์ ถวายน้ำท่าน แล้วขอให้น้ำเนี่ยเป็นยารักษาโรค ผมก็จะทำอย่างนี้ทุกวันตอนเช้า ... ดื่มน้ำแล้ว ก็ไม่พูดกับใคร สวดมนต์ก่อน ถวายน้ำให้หลวงพ่อก่อน ก็ค่อยๆ ดีขึ้น (19/1: p5, 15-20)

Overcoming the distressed feelings

The second strategy of the participants in the stage of pulling oneself together to fight was to overcome their distressed feelings of hopelessness, fear, and anxiety. The participants overcame the distressed feelings by alleviating them and *tham jai* (ทำใจ), which occurred concurrently.

Alleviating the distressed feelings

Alleviating the distressed feelings referred to the participants' attempt to reduce their feelings of hopelessness, fear, and anxiety. They might

ventilate these distressed feelings by talking to somebody in the family, the HIV-infected groups or friends, or healthcare providers. Some participants could lessen the distress by writing a diary, while other participants did something such as exercising, watching movies, listening to or playing music, reading books, or doing meditation to distract themselves from the feelings. These actions might distract their mind from the distressed feelings and make them relaxed temporarily. After the actions ended, the distressed feelings would sometimes return to their mind again with some decrease in the intensity. Some actions would facilitate the process of *tham jai* such as reading about Buddhist dharma.

A 32-year-old male participant had a motorcycle accident ten years ago and that was the time he found out his HIV-infection. He had multiple fractures on his leg. In the period that he lived with himself and had a suicidal idea, he tried to relieve his tension with many activities. He mentioned that these activities helped him feel better, so he could pass that period:

I begun reading Dharma books. It made me understand life... I started writing my diary. It might be since I wanted something to express my feeling, it made me feel better... I thought of the past and asked myself why I became like this. And I understood myself more... I learned to think and view the self... I tried to practice a sitting meditation... Sometimes I played the guitar all day. I loved playing guitar. I thought this matter helped me a lot and made me relax. I'd got a broken leg. While staying still on the bed, I did exercise like waving hands. I tried to find a way to do some exercise. Perhaps it could help. (6/1: p5, 4 – p7, 15)

ผมเริ่มอ่านหนังสือธรรมะ ทำให้เราเข้าใจชีวิต ... เริ่มเขียนบันทึก อาจเป็นเพราะเราหาที่ระบาย ก็ช่วยให้เรารู้สึกดีขึ้น ... ทำให้เรานึกถึงอดีตว่าทำไมเราเป็นอย่างนี้ ทำให้เราเข้าใจตัวเองมากยิ่งขึ้น ... รู้จักคิด รู้จักมองตนเอง ... ผมพยายามนั่งสมาธิ ... บางวันทั้งวันผมก็เล่นกีตาร์ไปเรื่อย ๆ ผมเป็นคนที่ชอบเล่นกีตาร์ ผมว่าตรงนี้นั้นมีส่วนช่วยอยู่เยอะ ทำให้เราได้ผ่อนคลายบ้าง แล้วก็ข้าหักเรานอนอยู่นี้ เราก็ exercise ขกแข้งขกขา หาทางออกกำลังกาย มันก็ช่วยได้มั่ง (6/1: p5, 4 – p7, 15)

A 35-year-old female participant had attempted suicide that caused her to suffer so much. She thought she would never do it again. She perceived that she was going to die because of HIV-infection, so she did whatever she wanted and she felt better. She said:

I thought if I must die, I would do everything I needed. Previously I rarely went traveling, so I did -- to go to another province, to see movie, to listen to music... I felt released while doing that. I thought of it [HIV infection] a bit when I stayed alone and felt lonely... But I didn't think of it throughout the day. (4/1: p5, 24-26)

เราก็คิดว่าถ้าเราจะต้องตาย เราอยากทำอะไร เราก็อทำ ก่อนหน้านีเราไม่ค่อยได้เที่ยว เราก็อไปเที่ยว ไปเที่ยวต่างจังหวัด ดูหนัง ฟังเพลง ... ก็สบายใจตอนเที่ยว สบายใจอยู่ เราจะคิดแว็บๆเวลาเหงา เวลาอยู่คนเดียว ... แต่จะไม่จมอยู่กับมันทั้งวัน (4/1: p5, 24-26)

Tham jai

The second sub-strategy to overcome the distressed feelings was *tham jai*. *Tham jai* is a word that is frequently used by Thai people. Thais usually tell themselves or others to *tham jai* to calm their minds when they feel distressed with unpleasant situations. From the Thai Dictionary (พจนานุกรมฉบับบัณฑิตยสถาน พ.ศ. 2525), ‘*tham*’ means ‘to do or to act,’ and ‘to make or to build,’ while ‘*jai*’ means the mind which functions to know, to feel, and to think, and ‘*tham jai*’ means to control the mind. Consistently with these meaning, *tham jai* that was derived from the participants’ view could be defined as the process of mental works to adjust or to control their thoughts and their feelings to try not to think, to think positively, to accept, and to realize the reality and to finally let go (ปลงตก). These were the meaning of *tham jai* stated by the participants.

Tham jai meant I didn’t think too much. I didn’t bother anybody... Just did as usual. That was all! I thought of death... Sooner or later everyone would die too. (10/1: p5, 13-19)

ทำใจ หมายความว่า ไม่ต้องคิดมาก ไม่ต้องให้คนอื่นเดือดร้อน ... ทำตัวเป็นปกติ เท่านั้นเอง ก็ทำใจเหมือนกับว่า เรื่องความตาย ... มันก็ตายทุกคน ต้องทำใจว่าจะตายเร็วหรือตายช้า (10/1: p5, 13-19)

I tried to think of good things and avoided thinking of bad things -- accept what already occurred. (13/2: p2, 32-33)

เราพยายามจะคิดในสิ่งที่ดี และพยายามไม่คิดในสิ่งที่ไม่ดี และยอมรับสิ่งที่เกิดขึ้นด้วย (13/2: p2, 32-33)

It was the mind-adjustment in order to adjust my emotions to the events I’d experienced. Then, I learned to accept what happened. (10/2: p2, 2-6)

เป็นการปรับความคิด ปรับความรู้สึกของเราต่อเหตุการณ์ต่างๆที่เราประสบ และยอมรับสิ่งที่เกิดขึ้น (10/2: p2, 2-6)

Accepted the truth that we couldn’t avoid. Everything would happen. I accepted the truth that I’d already been infected. So I *tham jai* that sooner or later every infected person must die. It was up to each one’s self-care. (17/2: p3, 25-29)

คือยอมรับความจริงว่าเราหลีกเลี่ยงไม่พ้นแล้ว อะไรมันเกิดมันก็เกิดจากตรงนี้ ยอมรับสภาพความเป็นจริงที่เกิดขึ้นว่าเราได้ติดเชื้อโรคนี้ขึ้นมา แล้วเราก็อทำใจว่า โอ้โรคนี้ก็จะฆ่าเรามันก็ตายกันหมดทุกคนแต่ระยะเวลาของมันมันจะสั้นหรือเร็ว ก็แตกต่างกันอยู่ที่เรารู้แลตัวเอง (17/2: p3, 25-29)

The participants began to engage in the process of *tham jai* with the conditions of emotional suffering and the realization of sooner death due to HIV infection. For the participants, *tham jai* was crucial in gaining control of themselves and their feelings in such a situation that caused great harm, threat, and loss to them as being HIV-infected persons. It occurred over and over again, but not continuously, along the process of fighting to live normally with HIV-infection. The participants worked it hardest in the early days, early weeks, or early months after knowing their HIV status to regain control of their thoughts and feelings. Then, it was relatively easier and occasionally happened when the participants encountered with some events in fighting for existence such as the economic hardship; discrimination/prejudice; the death of spouse, children, or a close friend; and an illness. Sometimes it occurred when they saw the picture of AIDS patients or when they were at leisure. One participant talked about his *tham jai* as follows:

During the first period, I madly managed my emotions. I had a terrible headache after knowing my infection. Then I began getting used to it and worked hard in order to forget it... I overdid it so much that I slept like a log. I forgot it for years... I thought of nothing. (13/2: p3, 2-4)

ช่วงแรกต้องทำใจหนักหนาสาหัส รู้แรกๆนี่ปวดหัวน่าดู มาพักหลังๆก็ค่อยๆชิน แล้วก็ทำงานหนักให้มันลืมไป...เราก็เริ่มโหมงานหนัก พอหัวถึงหมอนก็หลับ ก็ไม่ได้คิดอยู่ตั้งหลายปี ... ก็ไม่ได้คิดอะไร (13/2: p3, 2-4)

However, he still had to *tham jai* occasionally:

I always have *tham jai*. When having free time... I would think how long I could live. Always think about that... If I worked, did that or this, I wouldn't think. While watching TV and the pictures of AIDS patients full of swelling, I began thinking again. (13/2: p2, 17-18)

ต้องทำใจตลอด พอมีเวลาว่างเมื่อไร มันก็ต้องคิดถึงตัวเรามาก พอมีเวลาว่างปั๊บ ... เราจะอยู่ได้อีกกี่ปี ก็คิดถึงตลอด ... ถ้าเราทำงาน ทำโน่น ทำนี่ เราก็ไม่ได้คิด พอเราว่างๆก็คิด พอดูโทรทัศน์ เห็นคนเป็นเอดส์เป็นตุ่มนั่นตุ่มนี่ ก็คิดถึง (13/2: p2, 7-18)

Tham jai has four properties: modes of *tham jai*, degree of accomplishment, degree of difficulty, and duration. *Tham jai* consisted of four modes: trying not to think, thinking positively, accepting, and *plong/plong tok* (ปลง/ปลงตก). The participants might use one, or more, or all modes for each engagement in the *tham jai* process. The degree of accomplishment ranged from none, partially, to completely. The degree of difficulty ranged from easiest to hardest. And as for the duration, which was the period that the participants used to completely accomplish

tham jai in each engagement, it ranged from rapid (a few minutes) to prolonged (a few months).

Completely accomplishing *tham jai* was defined by the participants as the situation in which they could forget or stop thinking about HIV/AIDS. Some examples of such definition were stated in the following quotations:

Absolute *tham jai* meant I didn't think of AIDS... I just thought that it was the ordinary matter. We were born so we must get old, sick and finally die. I felt like it was nothing at all...I didn't think too much. Just thought that if I got sick, I would try to cure it. However, if it was unable to cure, I would die. That was all. (15/1: p10, 2-15)

ทำใจได้เต็มร้อย คือ ผมไม่คิดเลยเรื่องเอดส์ ... คือ เราคิดว่ามันก็เป็นธรรมดาแหละ ก็ต้องมีเกิด แก่ เจ็บ ตาย รู้สึกเฉยๆ ... ไม่ได้คิด คิดว่าป่วยก็รักษา ถ้ารักษาไม่หายก็ตาย คิดแค่นี้ (15/1: p10, 2-15)

Accomplishing *tham jai* meant that I felt and thought like I was not infected, since I could forget about it sometimes. I had lots of things to do. I also had to think of many things. So it was a feeling like I had no free time to think of my infection... ..It was like I had forgot it. (3/2: p5, 26 – p6, 4)

ทำใจได้ คือ ในความรู้สึกที่คิดว่า ตัวเองไม่ได้ติดเชื้อ เพราะว่าบางครั้งมันลืมนะค่ะ เรามีอะไรต้องทำหลายอย่าง เราต้องคิดอะไรตั้งหลายอย่าง มันก็เลยมีความรู้สึกว่ามันไม่มีเวลาว่างที่จะไปคิดว่าตัวเองติดเชื้อ ... มันเหมือนกับว่าเราลืมมันไป (3/2: p5, 26 – p6, 4)

However, after they could completely accomplish *tham jai*, they might have to engage in *tham jai* again when they encountered some difficulties or some events.

In the stage of pulling oneself together to fight, the participants did *tham jai* with their HIV-infection that they perceived as a terrible disease. They worked harder in a longer period when compared to the next stage, stage of fighting for existence. The time they took in *tham jai* in this stage ranged from a few days to a few months. Some intervening conditions such as family, friends, or learning Buddhist teaching, seemed to be the variables influencing the duration of *tham jai*.

Trying not to think. Trying not to think, the first mode of *tham jai*, referred to an effort of the participants to stop thinking about the unpleasant events or anticipated fear and anxiety. Some participants called it as 'emptying the mind' (*tham jai wang*) and they performed it through meditation as mentioned by a male participant as follows:

I had to *tham jai*... *tham jai* as meditation, doing a meditation, emptying the mind (*tham jai wang*), and stopping thinking. If I was able to accomplish *tham jai*, I could get along with the environment. (10/1: p3, 26-28)

เราต้องทำใจ ... ทำใจเป็นสมาธิ นั่งสมาธิ ทำใจว่างๆ ไม่ต้องคิด ถ้าทำใจได้ ก็ปรับตัวกับสิ่งแวดล้อมได้ (10/1: p3, 26-28)

Another male participant, a father of two sons, narrated his process of *tham jai* in the first few days after he had learned he had HIV-infection. He utilized the mode of trying not to think. He made some decision about his life. His concerns for the family, his responsibility to the family, and keeping busy with work appeared to play some role in his process of *tham jai*.

It seemed like sadness. Like I had lost something. I must die. I couldn't live long, but I had to look after my children. I still had to take care of my Mom and children. So I decided that let me die when the time came. While I was still healthy, I must work hard till my body couldn't bear it. *Tham jai* by stopping thinking. While working, I didn't think, I tried not to think. (13/1: p4, 13-24)

มันรู้สึกว่ เสียใจ เหมือนกับสูญเสียอะไรไป ต่อไปเราจะต้องตาย อยู่ได้ไม่นาน แต่เรายังมีภาระเรื่องลูก มีภาระต้องเลี้ยงดูแม่ ลูก ผมก็ตัดสินใจว่า ถ้าจะต้องตายก็ให้มันตายไป เมื่อยังแข็งแรงอยู่เราก้ทำงาน จนเราทำไม่ไหว ทำใจไม่คิดอะไร พอทำงานไปเราก้ไม่คิด พยายามไม่คิด (13/1: p4, 13-17)

Thinking positively. Thinking positively, the second mode of *tham jai*, meant to think of the situation in a positive or a hopeful way, and not to think in the disadvantageous way or helpless way. Some participants tried to think that they had some advantages. HIV infection was just a disease or an illness, or everything would be manageable or get better. Some participants used both trying not to think and thinking positively. These can be seen in the following quotations:

Tham jai for 2-3 days, I tried not to think. Whatever will be, will be. I came here (a hospital) because I'd heard that there was ARV drug right here. It was better than having nothing and waiting for death to come. I knew it, so I felt released... At this point I could afford it. I had money to pay for medicine. Having medicine, there was no problem. I just thought I had hypertension or diabetes. (13/1: p3, 7-12)

ทำใจอยู่ 2-3 วัน ก็พยายามไม่คิด เป็นอะไรก็เป็นกัน มาที่นี้ (โรงพยาบาล) ก็รู้ว่าที่นี่มียาต้านไวรัส เราก้สบายใจได้ ดีกว่าไม่มียาแล้วรอวันตาย เรารู้เราก้สบายใจ ... อันนี้เรามีพร้อม มีเงินซื้อยา มียา กิน ก็ไม่มีปัญหา เราก้คิดเสียว่าเราเป็นโรคความดัน โรคเบาหวาน (13/1: p3, 7-12)

I thought I was only sick. I thought like this. To think that I had AIDS, things would seem to be worse. I would be worried that I would die surely. But if I just thought I was sick. I would recover after seeing the doctor. I just thought like this. (14/1: p14, 10-13)

เราคิดว่าเราแค่ไม่สบายเฉยๆ คิดแค่นั้น ถ้าไปคิดว่าเราติดเชื้อ เราเป็นเอดส์ มันจะไปกันใหญ่ มันจะไปอีกชั้นนึงเลยว่ เราต้องตายแน่ๆ แต่ถ้าเราคิดว่าเราไม่สบาย เราไปหาหมอ เราก้หายแล้ว คิดแค่นี้แหละครับ (14/1: p14, 10-13)

Accepting. Accepting, the third mode of *tham jai*, referred to an acceptance that whatever happened had already happened, and it could not be

changed, or an acceptance of one's condition. It also referred to an acceptance of whatever that would happen in the future. A male participant and his spouse were both HIV-positive. He tried to accept it and encourage his spouse to accept it as well. He said to his wife as follows:

HIV infection had just occurred to the two of us. It would die with us either... I meant I accepted this situation...without discouragement. Like I knew what I was... I accepted the truth since it had already happened. I couldn't change or do anything anymore. (17/1: p1, 16-23)

ยังไม่ว่ามันก็เป็นอยู่กับเราสองคน มันจะตายก็ตายไปกับเรา ... คือยอมรับสภาพก็แล้วกัน ... ไม่ต้องไปท้อถอย คือเป็นเรารู้ว่าเป็น...คือยอมรับสภาพความจริงที่เกิดขึ้น เพราะมันเป็นไปแล้ว เราไม่สามารถจะไปเปลี่ยนแปลงทำอะไรมากไปกว่านี้ (17/1: p1, 16-23)

An acceptance of being HIV-infected might result in problem solving as appeared in some participants' statements:

I knew that I was [HIV] infected, so I must accept it. However, I must avoid thinking of it throughout the day. I couldn't do like that. I must behave as usual... but I still had to listen to the doctor about what kind of treatment I should have. (10/2: p4, 21-24)

เรารู้ว่าเราเป็น[ติดเชื้อ HIV] ต้องยอมรับว่าเป็น แต่ต้องไม่คิดว่าเป็นอยู่ทั้งวัน ทั้งวันไม่ได้ มันต้องทำตามปกติ ... แต่ก็ต้องฟังว่า ต้องรักษาแบบไหน (10/2: p4, 21-24)

As it [HIV infection] had already happened, and we couldn't solve the problems, so we should manage as well as we could. We must change the problem to be...like... what we could do the best. (14/2: p1, 19-22)

ในเมื่อมัน [การติดเชื้อHIV] เกิดขึ้นแล้ว แล้วปัญหามันแก้ไม่ได้ ก็เอาปัญหามาทำใหม่ให้ดีขึ้น เอาปัญหามาเป็นข้อที่แบบว่า ... ทำยังไงก็ได้ตอนนี้ให้มันดีที่สุด (14/2: p1, 19-22)

Plong or Plong tok. *Plong* or *plong tok* was the last mode of *tham jai*. Some participants mentioned *plong/plong tok* as a way to overcome the state of despair. According to their opinion, *plong/plong tok* was one of the *tham jai* process. It was *tham jai* about life and death. It was a process of thinking that began with contemplating about life and death, followed by realizing the reality of the uncertainty of life that everyone must die in some day, and then making a decision to let it be. *Plong/plong tok* seemed to occur after the participants could accept their situation. A participant expressed his idea of *plong tok* as follows:

Plong tok ... I meant... Although I didn't catch this disease, I may get another illness. I still must die. It was just like a resignation. I must die no matter what disease I'd got. What it needed was the time. Sooner or later, humans couldn't escape death. (17/2: p4, 5-9)

ปลงตก มันปลงกับชีวิต...หมายความว่า ถ้าเราไม่เป็นโรคนี้นี้ เป็นโรคอื่นมันก็ตายเหมือนกันนะ มันก็เหมือนกัน เป็นการปลงตก ไม่ว่าเป็นโรคนี้นี้หรือโรคไหนก็ตายเหมือนกัน มันอยู่ที่ต้องการเวลาเท่านั้นเอง มันจะช้าหรือเร็ว มนุษย์เราหลีกเลี่ยงไม่ได้ (17/2: p4, 5-9)

He continued describing that *plong tok* was like *tham jai* about the way of life.

Plong tok also meant *tham jai*. It was about death, living, and the way of life. The “birth-aged-illness-death” was the fact we couldn’t escape. I was resigned to my health... Just like it (HIV) was now with me, so I couldn’t avoid it... I was resigned that sooner or later I would die certainly. (17/2: p4, 11-17)

ปลงเป็นการทำใจเหมือนกัน มันเป็นเรื่องตาย เรื่องการดำเนินชีวิต วิถีชีวิต การเกิด แก่ เจ็บ ตาย เป็นเรื่องหลีกเลี่ยงไม่ได้ ปลงต่อสภาพสังขารตนเอง ... เหมือนกับว่า ทำใจว่าแล้ว(HIV)อยู่ มันหลีกเลี่ยงไม่ได้แล้ว ... คือปลง มันจะช้าจะเร็วก็ตายวันยังค่ำ (17/2: p4, 11-17)

Another participant used the term *tham jai* and *plong tok* interchangeably. He thought that *tham jai* and *plong tok* were the same things as could be seen in his quotation:

Plong tok was just like death was the simple thing. I behaved as usual. Getting HIV ...I would die someday. I kept on normal behavior and avoided thinking. I worked when I got a job. So I was not worried... I thought of nothing. (10/1: p5, 7-11)

ปลงตก เหมือนตายเป็นของธรรมดา ทำตัวเป็นปกติ มีHIV ชักวันเราก็ตาย ทำตัวเป็นปกติไปเรื่อยๆ ไม่ต้องคิด มีงานก็ทำงาน ไม่ต้องคิดมาก ... ไม่ต้องคิดเลยซักอย่าง (10/1: p5, 7-11)

He also described *tham jai* in the same way as *plong tok*, as can be seen in the following statement:

Tham jai meant now I didn’t think too far. I didn’t bother anybody... Just did thing as usual. That was all! I thought of death... Sooner or later everyone would die. (10/1: p5, 13-19)

ทำใจ หมายความว่า ไม่ต้องคิดมาก ไม่ต้องให้คนอื่นเดือดร้อน ... ทำตัวเป็นปกติ เท่านั้นเอง ก็ทำใจเหมือนกับว่า เรื่องความตาย ... มันก็ตายทุกคน ต้องทำใจว่าจะตายเร็วหรือตายช้า (10/1: p5, 13-19)

Finding the meaning in living

Finding the meaning in living was a cognitive process in which the participants searched for what was significant in their lives and made a decision about how to live or what to be done in the rest of their lives. The condition that led the participants to move into this process was the realization of sooner death. Accepting and *plong/plong tok*, which were the two modes of *tham jai*, were also the condition that facilitated this process. When the participants could discover their meaning in living, it would inversely foster the accomplishment of *tham jai*. For instance, the

statement of a male participant, a father of two sons, reflected on his realization of sooner death, and then he got into the process of *tham jai* and finding the meaning in living. These two processes were closely running together and seemed to facilitate each other as described in the following statements:

Already *tham jai* with it. What would occur, just let it occur. When still alive, I would look after my children and work for them until I couldn't work anymore. (13/1: p2, 31-32)

ก็ทำใจมาแล้ว เป็นไงก็ต้องเป็นกัน ถ้าเรามีชีวิตอยู่ เราก็ดูแลลูกทำงานเพื่อลูก จนกว่าจะทำไมไหว (13/1: p2, 31-32)

I just thought that if death came, I must die. Everyone must die. When still alive, I should make life worthy. I just thought like that...so I stopped thinking about it since then. Whatever will be, just let it be. (14/1: p4, 14-27)

ผมก็คิดว่า ถ้ามันถึงเวลาตาย มันก็ตายเองแหละ ทุกคนเกิดมาก็ต้องตายทุกคน เวลาอยู่เราทำชีวิตให้มันดี ให้มีค่า ผมก็คิดอยู่แค่นั้น ... ผมก็ไม่คิดอะไรตั้งแต่บัดนั้น มันจะเกิดอะไรก็ให้มันเกิด (14/1: p4, 14-27)

The process of finding the meaning in living was composed of three sequential actions: **considering about one's situation, realizing the worth of self and life, and creating a purpose of life.** The participants began with considering and reconsidering about one's situation, one's life in the past, and one's concerns. The consideration again and again made some participants understand themselves and their problems better. Some of them could view the problems they would encounter and eventually find a solution. Some participants thought of those whom they loved and cared for especially those who were under the patronage of them such as children and parents. Then, the participants could realize the meaning and the value in living and decided to live with some purposes.

The ways in which the participants found the meaning of their lives were different according to individual conditions. Some participants decided to devote themselves to the family, HIV-infected people, or drug-addicts (in the case the participants became HIV infected via intravenous drug use). Some participants intended to create valuable work for HIV-infected people and the society. Some of them set their goal as self-reliance. They decided not to bother their family, and they wished to help both the family and society if having a chance. Moreover, some participants would like to spend their lifetime living happily with their family, friends, and work.

The participants who had young children or aged parents and were the family's breadwinner usually decided to devote themselves to the family. Their process of finding meaning in living was narrated in these statements:

At first I felt sorry and cried, but then I realized that I still had young children. I must work for my children and think of them first. (13/1: p1, 1-3) ... I thought of my young children and my old Mom, how could they live after my death? So I just headed on working hard. (13/2: p1, 20-22)

เริ่มแรกรู้สึกเสียใจ ร้องไห้ มาคิดได้อีกที ชีวิตยังมีลูกเล็กๆอยู่อีก เราต้องอยู่ทำงานหาเงินเพื่อลูก คิดถึงลูกก่อน(13/1: p1, 1-3) ... เมื่อตัดสินใจคิดถึงลูกยังเล็กอยู่ แม่ก็ยังอยู่ ผมตายไปแล้วจะทำยังไง ก็ทำงานอย่างเดียว (13/2: p1, 20-22)

My parents had four children. I was the oldest. The others were still studying. At that time I had already quit school. When looking at my parents, Mom sold instant food and Dad was a mechanic. I thought they certainly wanted to rely on me when I grew up. They also wanted to have a rest and wished I would be their power instead. I thought like this. Sometimes my parents felt tired and cried but none of us knew it... I knew, so I thought like this... Thus, for the rest four to five years I would help my parents with whole heart... I thought of nothing since then. Whatever will be, let it be... I would spend my life that they said I had left for my parents. (14/1: p4, 5-31)

พ่อแม่มีลูกสี่คน ตัวผมเองเป็นคนโต น้องทุกคนก็ยังเรียนหนังสืออยู่ ช่วงนั้นผมออกจากโรงเรียนแล้ว หันไปมองพ่อกับแม่แล้ว แม่ผมขายข้าวแกง พ่อผมรับเหมาซ่อมรถ ผมก็คิดว่าเขาเลี้ยงผมมา เขาก็อยากจะพึ่งผมเมื่อผมโต เขาก็อยากจะพักผ่อน อยากจะให้ผมเป็นแขนเป็นขาแทนเขา ผมคิดแบบนี้ บางทีพ่อแม่ผมเหนื่อย นิ่งร้องไห้ ลูกเค้าไม่มีสิทธิรู้เลย ... ผมไปเห็นจุดนั้น ผมก็เลยคิดว่า ... เวลาที่เหลือ มันจะอยู่อีก 4-5 ปีเนี่ย ผมก็ช่วยพ่อแม่ทำเต็มที่ ... ผมก็ไม่คิดอะไรตั้งแต่บัดนั้น มันจะเกิดอะไรก็ให้มันเกิด ... ผมจะใช้ชีวิตผมที่เหลือ ที่เขาว่า 4-5 ปีก็ตาย ผมจะทำให้พ่อแม่ผมให้ได้ (14/1: p4, 5-31)

Some participants were young adults or late teenagers and were still single at the time they knew they had HIV. They lived with their family, and they were not the ones who had to support anybody in the family. On the other hand, some of them needed some support from their parents. These individuals decided to live by being self-supportive. They did not want to be the others' burden or to be dependent on others. Such decision about living may be seen in the following two statements of 27 and 32-year-old male participants:

I thought I was still fine, so I wouldn't bother anybody. I wished for no more, but just to be alive. I would take care of myself and not bother anyone. If I had a chance, I would take care of my parents and find a job. My life had no other wish. (6/1: p2, 21- 24)

ผมคิดว่า เรายังดีอยู่ เรายังไม่รบกวนใคร ไม่ขออะไรมา ขอมีชีวิตอยู่ ได้ดูแลตัวเอง ไม่รบกวนใคร ถ้ามีโอกาสก็อยากไปดูแลพ่อแม่บ้าง ชีวิตเรากำลังอยู่แค่นี้ ไม่ได้หวังอะไรมา แล้วก็หาเงินทำ (6/1: p2, 21- 24)

I began considering and reconsidering about the problems that would happen... How I could manage these problems in the future and how I could deal with the present in order to bear the future problems. Then I made a plan. During that time I realized how worthy the time was. I thought I nearly died, so I didn't want to be a burden of anybody. I didn't think of anything. I only focused on how to earn a lot of money. (12/2: p4, 14-22)

ผมเริ่มคิดทบทวน ผมทบทวนไปทบทวนมา ก็คิดถึงปัญหาที่จะเกิดขึ้น ... เราจะรองรับปัญหาในอนาคตได้อย่างไร เราต้องทำยังไงบ้างในปัจจุบันเพื่อรองรับปัญหาในอนาคตที่จะเกิดขึ้น แล้วก็วางแผน ตอนนั้นผมรู้ว่าเวลามีค่ามาก เรามองว่าเราใกล้จะตายแล้ว ช่วงนี้เราไม่อยากเป็นภาระของใคร ก็คือไม่ได้คิดอะไร คิดมั่งอย่างเดียวก็นึกหาเงินให้ได้เยอะๆ (12/2: p4, 14-22)

Another group of participants did not live with their family. Some participants were rejected by their family. Some participants had had a broken family since childhood. Each sibling was separated, so it seemed like they had no relatives. These participants had been searching for help from healthcare providers. They had a chance to receive additional information and advice. They were also invited to join the HIV-infected groups, which had just informally formed in some health service centers. The HIV-infected groups had been initially established by healthcare providers in order that infected persons could have a chance to help each other. Some participants had seen the model of helping others, while others had a chance to help other infected persons. Some participants were advised to adapt their HIV infection to make it useful to other infected persons. So, these participants had the will to live on. They could realize the meaning and the value of living. They also knew how to live as an HIV infected person. Some participants set their goal to dedicate the rest of their lives to help HIV-infected people or drug addicts.

One participant had set his goal for the rest of his life after joining HIV-infected group activities and receiving advice from a nurse who was the group's advisor. He discussed his intention as follows:

I don't know how long my life would be... Maybe in the next two years I would die or maybe I could survive for the next five years. But at this moment I would do the best. I only wished. I completely spend my lifetime on helping infected patients. (16/1: p10, 17-20)

ผมเหลือเวลาอยู่เท่าไรผมไม่ทราบ ... อาจจะอีก 2 ปี เสียชีวิต หรืออาจจะอยู่รอดไปอีก 5 ปี แต่เวลาที่ผมเหลืออยู่นี้ ผมขอทำดี ... กับผู้ติดเชื้อผมเต็มร้อยจริงๆ (16/1: p10, 17-20)

To join a group with HIV-infected people under social discrimination and prejudice, some participants became aroused to have a purpose of fighting for their existence in society as stated in the following quotation:

We must be alive. We were still human. How could we do something to let them know that we existed in the same world? We still existed...we had a responsibility to prove ourselves. (2/2: p2, 10- 15)

เราจำเป็นต้องอยู่ เรายังเป็นคน เราจะทำยังไงให้เค้ารู้ว่า เรายังมีตัวตนอยู่ในโลกใบนี้ ยังมีเราอยู่ ... เรามีภาระที่ต้องพิสูจน์ตัวเองแบบนี้ (2/2: p2, 10- 15)

A male participant had HIV infection from intravenous drug use. He knew that he had the virus when he intended to get into the therapeutic community of recovering drug addicts. People who got into the community were ones who used to be addicted to drugs and some of whom were HIV-infected as well. The program of the community therapy took an important part in his discovery of the meaning in living. He talked about the objectives of the program as follows:

It was a program for recovering drug addicts so that they could understand themselves, know about self, and not return to drugs. Apart from helping me stop taking drug, it could help me understand about life... This program had taught me a lot. (1/1: p4, 14-19)

เป็นโปรแกรมที่ใช้บำบัดฟื้นฟูคนที่เคยติดยาเสพติด ให้เข้าใจตนเอง รู้จักตนเอง แล้วไม่กลับไปใช้ยาเสพติดอีก ซึ่งนอกจากเลิกยาเสพติดแล้ว มันทำให้ผมได้เข้าใจชีวิต ... มันสอนผมหลายอย่าง (1/1: p4, 14-19)

He described the program that focused on teaching members of the community to do group activities, have responsibility for one's job and someone else, and care for each other. Furthermore, the aims of the program were to instruct the members to be partners for each other, warn and share feelings with each other, and be able to control and manage one's emotion in the right ways by sharing it with group. He learned that taking care of and help others would make him feel better. In addition, he experienced the model of the therapeutic community officials working. So, he realized self-worth and had a goal of life. He said the following:

I began to realize how worthy I was and what I would live for. At that time I even took an oath with myself that I would be a staff here till I died. I would devote my life to those friends. (1/1: p8, 23-25)

เราเริ่มเห็นว่าตัวเองมีคุณค่า เริ่มคิดได้ว่าตัวเองจะอยู่ไปทำไม ตอนนั้นถึงกับสัญญากับตัวเองว่า จะเป็นเจ้าหน้าที่อยู่ในนั้นจนวันตาย จะทุ่มเทให้กับน้องกับเพื่อนที่ตรงนั้น (1/1: p8, 23-25)

To find the meaning in living made them realize that their life was still worthwhile. They would find the solution to life and wish to live longer. Many of the participants wish they could live as long as possible. They had a goal in life and intended to do something with a good cause during the rest of their lives. Moreover, they had morale to fight against problems and obstacles in their life.

Intervening conditions

The conditions that influenced the process of pulling oneself together to fight were social support, healthcare providers, and individual attributes. The sources of social support were family, and HIV-infected groups and friends. The support would be in the form of acceptance from family, care, encouragement, advice or guidance, knowledge and information, and moral and spiritual support. Healthcare providers also gave these supports to the participants. In addition, healthcare providers initiated the groups of HIV-infected people and led the participants to these groups. These supports helped the participants experience relief, facilitated their entry into the process of *tham jai*, reduced their distressed feelings, and created hope and morale. Reciprocal support they had for each other made the participants feel self-worth and facilitated the process of *tham jai* and finding the meaning in living. The following examples demonstrate the influences of family and friends in their overcoming distressed feelings and finding the meaning in living.

A female participant gained morale and could accomplish *tham jai* when her family accepted and supported her as mentioned in her statements:

When Mom and sister knew it, they soothed me and said that I shouldn't worry too much...Firstly, I felt discouraged and afraid that they would find me disgusting me...Sister said she didn't...Mom also didn't. So, I had willpower. (20/1: p2, 7-15)

พอแม่ทราบ พี่สาวทราบ เขาก็ปลอบใจเรา ไม่ให้คิดมาก ... ที่แรกไม่มีกำลังใจ กลัวเขาจะรังเกียจ ... พี่สาวก็บอกว่า ... ไม่ได้รังเกียจนะ ... แม่ก็ไม่รังเกียจ ก็ทำให้เรามีกำลังใจ (20/1: p2, 7-15)

After I said what I'd like to speak out, I could *tham jai* with it. It was depressing to keep it in the bottom of my heart. After Mom came and talked to me, I asked her whether she felt disgusted, but she said "not at all"... She cheered me up. (20/2: p2, 32 – p3, 2)

พอหนูพูดอะไรที่หนูอยากพูดออกมา หนูก็ทำได้เลย ที่มันอัดอั้นในใจมันก็ไม่สบายใจ พอแม่เข้ามาพูดอย่างโน้นอย่างนี้ หนูก็บอกว่า แม่รังเกียจมั๊ย เขาก็บอกไม่รังเกียจ ... เขาก็ปลอบหนูทุกอย่าง (20/2: p2, 32 – p3, 2)

Another participant's *tham jai* was facilitated by his mother. His mother led him to think positively and see the reality of life:

Mom said, "We must die whatever sickness it was. Everybody had to get some disease after our birth, depending on what it would be. But for me, it was a good point. It was not like catching cancer, which was more suffering." ...Then I agreed. (12/2: p4, 31 – p5, 2)

แม่พูดว่า "คนเราเป็นอะไรก็ต้องตาย คนเราเกิดมาก็ต้องมีโรค ไม่ว่าโรคนั้นจะเป็นอะไรก็แล้วแต่ แต่ของเราดีอย่าง มันไม่เหมือนเป็นโรคมะเร็ง ทรมาณมากกว่า" ... เราก็ เออ ใช่ (12/2: p4, 31 – p5, 2)

He accepted and believed in what his mother said, and then he began reconsidering his situation and then created a sense of purpose in living.

A single male participant lived with his family. He explained the factor that helped him in *tham jai* as follows:

I think family is the most important... until I met this club [of infected persons] and I got friends, the more *tham jai* I had attained. Right here we talked about death as just a joke. (15/1: p5, 25 – p6, 5)

ผมว่าครอบครัวสำคัญที่สุด ... แล้วพอมาเจอชมรม(ชมรมผู้ติดเชื้อ) เจอเพื่อน เราก็ยังทำได้เร็ว ที่นี้เขาคุยเรื่องตายเป็นเรื่องตลก (15/1: p5, 25 – p6, 5)

Individual attributes were another condition that influenced the action and interaction strategies in the stage of pulling oneself together to fight. These attributes included developmental state, roll and responsibility in the family, personal belief, and lived experiences. The developmental states of the participants at the time they knew they were HIV infection varied. Some participants were adolescents, some were young adults, and others were adults. They might be single or married with or without children. These developmental states and their responsibilities in their family influenced the meaning they gave to their lives.

The participants' beliefs influenced their spiritual actions and mental works in reducing their distressed feelings. The experiences in learning and practicing Buddhist teaching seemed to facilitate the action of *tham jai*. Some participants had never learned it before, but reading and learning it during the time of suffering made them realize the reality of life, and this led them to acceptance and *plong/plong tok*, which are modes of *tham jai*. This is clearly stated in the following quotation:

I started reading doctrine books. I'd been interested in Dharma... Then I had a thought about "*Anicca, Dukkha, and Anatta*". I'd read and tried to understand about "*Anatta*." I thought about it in parallel with my present condition, so I

realized the truth. Yes, it was the reality. Nobody could escape this truth ...Just sooner or later. I also thought that I would take care of myself and rely-on myself. I wouldn't bother anyone. That was all. What would happen next, I could accept it. (6/1: p17, 4-11)

ผมเริ่มอ่านหนังสือธรรมะ ผมเริ่มสนใจธรรมะ...เราก็เริ่มเอามาคิด “อนิจจัง ทุกขัง อนัตตา” “อนัตตา” เนี่ย ตัวนี้เราพยายามอ่าน แล้วคิดไปด้วย บวกกับภาวะที่เราเป็นอย่างนี้ด้วย เราารู้สึกว่า เออ มันจริงนะ มันเป็นเรื่องจริงจริงๆ มันก็ไม่มีใครหนีพ้นไข่ม้อยอะ เพียงแต่ไปช้าไปเร็วเท่านั้นเอง บวกกับความคิดของตัวเอง ที่ว่า เราจะต้องดูแลตัวเอง ฟังตัวเอง ไม่รบกวนใคร หรือเป็นภาระให้ใคร ก็แค่นี้ ข้างหน้าจะเป็นยังไงก็ต้องยอมรับ (6/1: p17, 4-11)

“*Anicca, Dukkha, and Anatta*” is Buddhist teaching about “The Three General Characteristics of Existence.” It explains that all existences have three general characteristics: *anicca*, *dukkha*, and *anatta*. “*Anicca*” refers to “impermanence.” All existences are impermanent. They are always born and then decay. “*Dukkha*” refers to sorrowfulness or suffering. Since everything is impermanent, they are sorrowful and suffering. “*Anatta*” refers to “non-self.” All forms of existence are subjected to decay, so none of them can be a Self, an Ego, or a Soul (David-Neel, 1977: 25; Schumann, 1974: 42-47). When contemplating about the Buddhist teaching and considering individuals’ sufferings, they realized the reality of life and could accept what had happened or would happen to them in the future.

Another male participant mentioned that the Buddhist teaching was the most important thing for him to do *tham jai* and to have been living for over ten years with HIV. He said:

If I hadn't studied Buddhist doctrines, I couldn't *tham jai*. Unable to *plong* ... Couldn't stop thinking of it. Those who think of it every day, like for one or two days would feel more suffering. Those who never learned [about doctrine] couldn't *tham ja*. Only one month... they would die. (10/1: p8, 2-5)

ถ้าผมไม่ศึกษาธรรมะ ผมทำใจไม่ได้ ปลงไม่ได้...อดคิด คิดทุกวัน คนที่คิด คิดสองวัน หรือหนึ่งวันก็อยู่ไม่ต่อได้แล้ว คนที่ไม่ศึกษาทำใจไม่ได้หรอก ไม่ถึงเดือนเอง เรียบร้อย...ตาย (10/1: p8, 2-5)

However, not every participant had this experience, and some did not pay attention to it.

Consequences

The consequences of the participants' action and interaction strategies in the stage of pulling oneself together to fight were the reduction of distressed feelings, the changes in perceptions of HIV infection or AIDS, willingness to live, and realization

of self-worth and the worth of life. Moreover, they had hope, morale, and a purpose in living.

With the strategies of seeking help and overcoming the distressed feelings, the participants felt better and relieved. Some participants were accepted and supported by their family. They felt less fearful and less anxious and had the will to live. They received moral and spiritual supports from healthcare providers, friends, and their spiritually respected matters. Some participants had gained more helpful information and advice that changed their perceptions of HIV infection or AIDS. They saw that HIV infection or AIDS was not an instant death sentence as they had thought before. They could live for years if they cared for themselves and quit risk behaviors. HIV/AIDS was not easy to transmit to others, so there was no need to tell other people that they were HIV-infected. As a consequence, they had hope and morale to continue living. Some participants began seeing how they could live as an HIV-infected person, and other participants had a feeling of being human and having a social life again when they were part of the HIV-infected group.

In finding the meaning in living, the participants considered their situation and realized that they and their lives were still worthy for someone or something. They could find the solution to their lives and had some purposes in living.

In conclusion, the stage of pulling oneself together to fight was a period in which the participants turned themselves from flight; that is, avoiding facing or escaping their situations related to their HIV infection, to a ready state to fight for living. They moved into this stage with the realization of their sooner death and sufferings. At the beginning of this stage, they still perceived that HIV infection or AIDS was a terrible disease that was disgusting, could not be cured, and bring on death within a few days or a few years. But at the end of this stage, some participants' perception was changed. They gained more information and more knowledge about HIV-infection and AIDS that gave them hope for living. The participants' strategies in this stage included seeking help, overcoming their distressed feelings, and finding the meaning in living. These strategies not only made them feel relief and have some changes in their perception about HIV infection or AIDS but also constituted a ready state to fight for living. It was a state in which they realized their self-worth and the worth of life; and they had a will to live, a hope, morale, and a purpose in living.

Stage 3: Fighting for Existence

Fighting for existence was a stage in which the participants worked very hard to overcome many events or difficulties to continue their family's and their own lives and to attain their purposes in living. The participants had to face a lot of problems and they pushed all of their efforts to survive in these difficult situations. Stage of fighting for existence was a long-lasting stage that took many years. Some participants had spent their time on this stage since they started their fighting until the present time. Some participants could pass through this stage and move to the next stage, the state of living normally.

Causal conditions

The causal conditions that led the participants to enter the stage of fighting for existence were perceiving the possibility of years to live, realizing self-worth and the worth of life, having willingness to live, having a purpose in living, and having morale to fight their way of life. These conditions were the consequences in the previous stage. Some participants' perception about HIV-infection or AIDS had changed. Ones who had thought that they would have to get sick and die suddenly knew that they could live for years if they cared for themselves. And some participants had more knowledge about HIV/AIDS, such as how HIV caused them illness, how to care for themselves, and how the virus could be transmitted to others.

The reciprocal support in the previous stage made them realize their self-worth and enhanced their morale in fighting for living. The meaning they got in living created the sense of the worth of life and some purposes in living. So, they were willing to live to achieve their purposes in the rest of their lives. These conditions formed the ready state of the participants in encountering their situations to continue living.

Contextual conditions

The contextual condition that created the difficulties for the participants in living was social discrimination and prejudice. Some participants lost the job because the company needed HIV blood test in the recruitment process, or required its employers to have the test. Therefore, it was difficult for them to find a job, which was necessary for living. Some health centers refused to give care or treatment or an

operation to them when it was needed, while others received the care and treatment needed in an unwilling manner. Landlords refused to let houses to them. Moreover, some participants were affected by the “Monitoring and Controlling Patients Who Caught Serious Infectious Diseases” Act of 1985. They had to run away from being monitored by the public health officials according to the Act and find another place where nobody knew their HIV status to live and work.

However, there were several HIV-infected groups and social organizations working on HIV/AIDS gradually developed in Thai society. These groups and organizations had purposes to help HIV-infected people and AIDS patients by giving encouragement, counseling, care, and materialistic support. They also aimed to raise the awareness of Thai people about HIV infection or AIDS, and the infected peoples’ problems. An HIV-infected group in Thai society was first developed in 1991, and then several such groups were rapidly and widely established to form a network around the country.

Action and Interaction Strategies

The action and interaction strategies of the participants in this stage included seeking fundamental factors for living, learning about HIV/AIDS, managing health and illness, keeping up morale, and concealing and disclosing their HIV-status. These strategies were continuous in nature, highly interrelated, and two or more of them were mostly found continuously running in a situation. For example, when the participants had an HIV-related illness, they had to manage the illness, learned more about HIV/AIDS, and kept up their morale. These were evidenced by the data provided by the participants, which would be delineated in the following parts.

Seeking fundamental factors for living

Seeking fundamental factors for living referred to the actions that the participants took to meet their families’ and their own basic needs for living. The fundamental factors for living one usually called in Thais as ‘*paj jai si*’ or ‘the four factors’: food, residence, clothes, and medicine. Medicine might be the following necessary factor when the participants became sick or when their CD₄ level decreased. The problems many participants faced especially those who left their homes or had to run away from being monitored by the public health personnel, was about food and living place in each day. One female participant stated as follows:

I could do everything for survival. I meant to have a place to live, have food to eat, have a place to sleep. I just got the *paj jai si* except for medicine. Maybe I couldn't get drugs. I just wanted only food, living place, and clothes. (2/2: p5, 12-14)

ทำยังไงก็ได้ให้อยู่ได้ เอาตัวรอด ก็คือ มีอยู่ มีกิน มีที่หลับนอน ได้ปัจจัยสี่ ยกเว้นยา คือบางทียาเราอาจจะไม่ได้ คือ มีอาหาร ที่อยู่ เครื่องนุ่งห่ม (2/2: p5, 12-14)

Another fundamental factor for all participants was money because it could be exchanged for those four factors and other factors necessary in living. Some participants sought and saved money for their children's education, and others for their future medical expenses. The actions of each participant in seeking the fundamental factors for living were different depending on the conditions of individual resources such as family, socioeconomic status, education, and occupational skill. Moreover, they were up to each one's situation. The participants sought these fundamental factors by mobilizing resources, finding jobs, and working hard. The participants might use one or two or all of these sub-strategies. Sometimes they used this one, while at another time they used another one.

Mobilizing resources

Mobilizing resources meant the participants' attempt to seek and use available sources of support that may be drawn upon when needed. The participants sought support from many resources, both personal and social resources. The personal resources might be family and friends. The social resources might be HIV-infected groups, or governmental and non-governmental organizations, which provided help for sufferers and disadvantaged people and also HIV-infected people or AIDS patients.

Some participants who were young, had still not graduated, were still jobless, or those whose family rejected them when knowing about their HIV infection, had to mobilize resources to meet their basic physical needs during the first period after they knew about their infection. Some participants might use this sub-strategy at the time when they faced some trouble such as losing job, getting sick, or when their child or spouse got sick, and they could not work. The following are some examples of participants' seeking fundamental factors by mobilizing resources.

A 30-year-old female participant had to move away from her family and community because her HIV-status was disclosed. She had to face many

difficulties alone. During the first period, she sought support from friends who did not know about her infection. Furthermore, She had to conceal her infection and tried to site many reasons why she had to do what she was doing. She talked about her life during that time as follows:

At night I slept on the bus. During that time there was 24-hour bus service offered. I stayed on the bus for a few days. Sometimes I stayed with my friends... Just told them I visited them and asked to stay about three or four days. I stayed with my friends and helped them working in their restaurant. Sometimes I stayed at the restaurant... I just asked for meals and sleeping place. I asked for nothing else. My friends asked me whether I had any problem. But I just replied that I quarreled with my family. (2/1: p15, 17-24)

คืนนั้นนอนบนรถเมล์ สมัยนั้นมีรถเมล์ 24 ชั่วโมง ใช้ชีวิตอยู่บนรถเมล์หลายวัน บางทีก็ไปนอนบ้านเพื่อน ... ก็บอกเพื่อนว่า มาเยี่ยม ขอนอนด้วยหน่อย 3-4 วัน ก็ไปอยู่กับเพื่อน ไปช่วยเพื่อนที่เขาทำร้านอาหาร แล้วก็นอนในร้านเพื่อนมั่ง ... แล้วบอกเพื่อนว่า เราขอแค่กินและที่นอน ไม่เอาอะไรอย่างอื่น เพื่อนก็บอก “เอ็งมีปัญหาอะไรหรือเปล่า” เราก็บอก ทะเลาะกับที่บ้านมา (2/1: p15, 17-24)

Some participants were accepted and supported by their family (Parents and siblings). They usually earned money to support themselves, but at times they had financial problems, lost their jobs or got sick and could not work. They still received help such as daily expenses and treatment expenses from their family as explained by a male participant as follows:

I had an elder sister who always helped me whenever I had a problem. While I was still working, I had moved out of my home. I sometimes had no money for the rent, so I told her and she gave me money. She usually watched over me and was worried about my living. When I got sick, she gave me money so that I could go to the hospital. (15/1: p8, 30-33)

ผมมีพี่สาวที่คอยช่วยเหลือผมตลอดเวลา เวลาเราขาดเหลืออะไร ตอนนั้นเราทำงาน มาอาศัยอยู่นอกบ้าน ไม่มีเงินจ่ายค่าเช่าห้อง ก็ไปหาพี่สาว พี่สาวก็ให้มา แกจะคอยเป็นห่วงว่าเป็นยังไงบ้าง ไม่สบาย เป็นโน่น เป็นนี่ แกบอกเอาเงินไปหาหมอนะ (15/1: p8, 30-33)

Some participants had disadvantages such as low education and poverty. Some of them were rejected and forced to move away from the family, while other participants had HIV-infected children and spouse. They tried to find jobs and rely on themselves. However, they sometimes had problems that needed others' support. Therefore, these participants would seek support from the social resources that would be staff or agencies in the public sector or private sector, including medical staff and social welfare department in the hospital they used to go to. They would persistently ask for help from these resources till they received some support. This

group of participants not only gained the fundamental factors for living but also received moral support. In addition, they could work for other sufferers; thus, they felt they were valued and proud afterwards.

A female participant and her husband were laborers at a construction site. Her spouse deserted her and their child when the baby was about one and a half years old. During that time, the baby began to be sick, so she had to look after her baby and was unable to work. She needed work so she tried to find some place that could help her take care of the baby. This participant had known that the Phayathai House provided nursery service and the Rajavitee House offered childcare; therefore, she tried to ask them to accept her baby. She told her story of that time as follows:

I brought my baby to the Rajavitee House. I'd like to work... the Rajavitee House rejected me...they called the Phayathai House. The Phayathai House asked me if the baby was mine, and I said yes. I'd like someone to take care of my baby because I would find a job and nobody looked after him. I told them like this...but they rejected me. At that time it was 9 p.m. I was sitting in front of the office building, I had nowhere to go, so I just sat on the footpath. There was a bakery delivery staff who found me. She asked me why I was sitting there. I replied that I went (to the Rajavitee House) in order to ask for baby care and they rejected me. I just needed a job. Then she asked where I would go because it was very late at that time. She wondered why my baby and I were sitting like this. I answered her I had nowhere to go. I decided I would sit till the next morning and ask them again. She suggested I shouldn't do that. If they turned me down the first time, there wouldn't be the second. She, thus, took me to stay with her. The next day I left her house, and I returned to the Rajavitee House. They said "Oh! You were back here again." So, I burst into tears and said please... I wanted to work. I just wanted someone to look after my baby. Please accept my baby. But they still turned down my request and offered to bring me to the Department of Public Welfare by their van. At the department, they urged me to go back home, but I refused. So, they advised me to stay at the emergency shelters. I thought so... Therefore, they took me there, and I stayed there since then. (11/1: p5, 30 – p6, 30)

หนูพาลูกไปที่บ้านราชวิถี หนูอยากจะทำงาน ... บ้านราชวิถีก็ไม่รับ ... เขาก็โทรไปที่เด็กอ่อน พญาไท เด็กอ่อนพญาไท เขาก็ถามว่า เป็นลูกเธอหรือ หนูบอกว่าใช่ค่ะ หนูอยากเอาลูกมาฝากเลี้ยง หนูจะทำงาน ไม่มีคนดูแล หนูก็บอกเขาไปอย่างนี้ ... เขาก็ไม่รับ ตอนนั้น 3 ทุ่มแล้ว หนูก็นั่งอยู่หน้าตึกบ้านพญาไท หนูไปไหนไม่รอด หนูก็นั่งอยู่ตรงขอบริมถนน ก็เลยมีคนที่เขาเอาขนมมาส่ง เขาไปเจอ เขาก็ถามว่า หนูทำไมมาอยู่อย่างนี้ หนูก็บอกว่าหนูเอาลูกมาฝากเขา เขาไม่ยอมรับ หนูอยากทำงาน เขาก็บอก แล้วนี้จะไปไหนต่อ มันดึกแล้วนะ พาลูกมานั่งทำไมอย่างนี้ หนูบอกหนูไม่รู้จะไปไหน หนูก็นั่งเฝ้า เฝ้าแล้วหนูจะลองเอาไปฝากเขาอีกที เขาก็แนะนำว่าอย่าเลย ในเมื่อไปครั้งแรกแล้วเขาไม่รับ เขาก็ไม่รับหรอก เขาก็เลยพาไปนอนบ้านเขา พอเช้ามาหนูก็ลาเขาออกมา หนูไปบ้านราชวิถีอีก บ้านราชวิถีก็บอก มาอีกแล้วหรือ หนูก็ร้องไห้ร้องไห้เลยตอนนั้น หนูบอกพี่...หนูอยากทำงาน หนูอยากมีคนเลี้ยงลูก รับเหอะ เขาก็รับไม่ได้ ... เอาอย่างนี้ก็ได้แล้วกัน จะส่งหนูไปที่กรมประชาสงเคราะห์ เขาก็เอารถพาไปส่ง กรมประชาสงเคราะห์ก็จะยื่นคະขอให้หนู

กลับบ้าน หนูก็ไม่ยอมกลับ เขาก็บอกว่า เอาอย่างนี้ไปพักที่บ้านพักฉุกเฉินมัย หนูก็บอกว่าไป เขาก็ส่งหนูไป ก็อยู่เลย (11/1: p5, 30 – p6, 30)

The emergency shelter was the shelter that gave aid to the suffering children and women. It provided room, meals and healthcare. Moreover, it provided job training. This participant had stayed there for years until her child became sick and died from AIDS. She, afterwards, worked as an official, who took care of the sick in that emergency shelter.

Finding jobs

Having a job meant a lot to the participants. It meant having self-support and being self-sufficient, not being a burden on others. Some participants defined the meaning of having a job as their life. It meant that they were still worthwhile. Many participants confronted the problem about finding a job. They often lost their opportunity in working due to the blood test in the office or during the recruitment procedure. This problem made them hurt, depressed, and discouraged.

The participants needed to find a job which did not require blood test. Therefore, those jobs were usually minor employment and lower than their educational degree. Sometimes, they worked for small companies, which had no health welfare for the workers. A 27-year-old male participant, who earned a Bachelor's degree, described his problem in finding a job:

Once I tried to find a job, it was very hard because many companies asked for blood test... I felt strained. Though I had power and thinking ability, I couldn't be accepted just because of the barrier of blood test... Though I could pass the interview and paper exam... Some big companies also checked my horoscope by their fortune-teller and I could pass this level. Until I had to have blood check-up, I couldn't pass it. I felt it was unfair for me. I had no symptoms, even skin symptoms... You see? I had no symptom shown, and I was just like ordinary people. However, I couldn't go to work because of my blood test. They had assessed my value too low. (12/1: p13, 3-23)

ครั้งนึงผมจะหางานทำ หายากมาก เพราะบริษัทหลายบริษัทจะตรวจเลือด ... รู้สึกเครียดมาก ทั้งๆที่เรามีแรง เรามีความคิด แต่เราเข้าไปทำไม่ได้ เพราะว่าเราติดเรื่องการตรวจเลือด ... ทั้งๆที่เราสอบสัมภาษณ์เข้าไปได้ เราสอบข้อเขียนเข้าไปได้ ... บริษัทใหญ่เขามีทั้งหมดดู มีอะไร เราผ่านหมดเลยนะ จนกระทั่งเจอด่านนี้ ด่านตรวจเลือดเราไม่ผ่าน ผมรู้สึกว่ามันไม่ยุติธรรมกับเรา ทั้งๆที่เรามีแรง เราไม่ใช่ว่ามีอาการอย่างอื่นเข้ามา อาการทางผิวหนังผมก็ไม่มี ... พี่ดูอาการผมไม่มีเลยก็เหมือนคนปกติทั่วไป แต่เราไม่สามารถที่จะไปทำงานได้ เพราะมีแค่ผลเลือด แค่นี้หรือ มันตีค่าเราต่ำไป (12/1: p13, 3-23)

He began working as a volunteer for HIV-infected group again. When there was a social security in Thai society and afterwards the government launched the self-security project by having security through organization or companies a year before. This project got rid of the problem regarding medical expenses while getting sick. So, he found a job in order to gain the self-security:

When there was social security, I really needed it. What I did was applying for security guard position. I was working as a guard... At that time there was an announcement about self-security... I studied the condition for self-security. I had worked as a security guard for a whole year. Then I quit the job and started my self-security payment. (12/1: p15, 3-11)

พอมีประกาศเรื่องประกันสังคมเข้ามา ผมก็อยากได้มากๆเลย จะทำยังไง ผมก็ตัดสินใจเข้าไปเป็นพนักงานรักษาความปลอดภัย(ร.ป.ก.) ไปเป็นยาม ... ก็ตอนนั้นมันเริ่มมีประกาศว่าสามารถประกันตนเองได้ ... ผมไปดูเงื่อนไขว่าจะทำยังไงถึงจะประกันตนเองได้ ผมไปทำงาน ร.ป.ก. ปีหนึ่งเต็มๆเลย พอครบปีผมลาออกเลย แล้วผมก็มาส่งตัวเอง (12/1: p15, 3-11)

Another male participant knew that he was infected when he nearly graduated with the higher vocational certificate. He stopped studying because he thought he would be alive for a short while longer. He applied for a job using the vocational certificate and lost a chance to work due to blood test. He felt very hurt at that time. When the researcher asked what he did during that period, he replied:

I tried to do everything that I wouldn't bother others... Even riding motorcycle to make a living... I didn't think of applying for another job. I didn't think of working in a company for a few years. During that time, I earned money for myself by repairing television or radio... I did everything that made me survive. (6/1: p29, 16-24)

ผมพยายามทำอะไรก็ได้ที่เราจะไม่รบกวนคนอื่น ... ก็ถึงได้ไปขี่มอเตอร์ไซด์รับจ้าง ... ผมไม่คิดจะไปสมัครงานที่อื่น ไม่คิดจะทำงานบริษัทเลยเป็นปีสองปี ช่วงนั้นก็หารายได้ งานซ่อมทีวี เครื่องเสียง ... ทำอะไรก็ได้ที่ทำให้ตัวเองรอด (6/1: p29, 16-24)

Some participants worked every job available to earn money for their family and their own living such as cleaning dishes, being a housemaid, riding hired motorcycle, being a security guard, or being a craftsman, etc. Some participants changed many jobs or did many jobs all together, as can be seen in the following quotation:

I had low education. When applying for jobs, they usually accepted those who had high school or vocational certificate. ... I worked as a housemaid and earned 200 or 300 Baht per day... I also worked as document packing staff, just managed the package and brought it to the post office. I earned a bit from this job... Furthermore, I sold camphor hangers or little gifts. I made the hangers when I had free time and sold them after finishing. I just made camphor hangers and ribbons to decorate the garlands. (3/1: p18, 2-25)

หนูจบวุฒิน้อย เวลาสมัครงานเค้ามักจะรับ ม.6 หรือ ป.ว.ช. ... หนูไปทำงานตามบ้าน พวกกวาดดูบ้าน ได้ค่าจ้างต่อวันวันละ 200-300 บาท ... แล้วก็มีการพวกแพ็คเอกสาร ไปเย็บไปแพ็คส่งไปรษณีย์ให้เขา ก็พอจะมีรายได้จากตรงนี้บ้าง ... นอกจากนั้นจะขายการบูร ขายของบ้าง พอว่างก็นั่งทำ ทำเสร็จก็ขาย ที่ทำขายก็มี การบูร และริบบิ้นที่เค้าเอาไปร้อยพวงมาลัยสด (3/1: p18, 2-25)

Those participants who intended to devote themselves to help other infected persons had a job as volunteers in HIV-infected groups or organizations that provided support to HIV-infected people or AIDS patients. They received salary or daily allowance. They also had a chance to be a speaker in many places to share their life experiences with HIV. This work would benefit both the participants and the society. The participants had a chance to review their lives and gained more understanding of self. While meeting many good people, these participants could obtain valuable ideas and share their perspectives. Therefore, they would understand others. As for social benefits, there would be more understanding of HIV-infected persons. A female participant who worked for the Thailand HIV-infected organization network talked about her experience as a speaker as follows:

My first time of being a lecturer was about talking and sharing my experience. Previously I refused and thought it was not my business to explain my story to the others... But when they said I could earn money, I made up my mind and agreed with them. At that time, I couldn't live without the basic necessity factors, especially money. I thought money was the remuneration that I would gain from being a lecturer. However, the more I would gain was that the listeners would understand infected people more. We would have a chance to share opinions. ... I felt that there were not just some persons who objected to us. If we had a communication between us, we could understand each other. Being a lecturer had given me a lot of answers. I knew how to live with the infection. It made me understand the others and also made them understand me. (2/1: p36, 11-26)...While working as a lecturer, I was lucky to meet many good people such as doctors and journalists... Sometimes they were the conference organizers, while at other times they were also lecturers. I was impressed. We were talking or making a phone-call. (They said) I could ask them for advice. They'd like to help me. They could give me many suggestions. (2/2: p3, 26-29)

การเป็นวิทยากรครั้งแรก คือการไปพูดเรื่องประสบการณ์ชีวิตของตนเอง ตอนแรกหนูบอกไม่เอา เรื่องอะไรต้องไปคุยเรื่องของตัวเองให้คนอื่นฟัง ... เขาก็บอกว่า ได้ตั้งนะ หนูบอกว่างั้นเอา ตอนนั้นเราจะมีชีวิตอยู่ได้เราต้องการปัจจัย ปัจจัยที่ทำให้เราอยู่ได้ ก็คือเงิน ตอนนั้นคิดว่าเงินเป็นคำตอบแทนที่เราจะได้จากการเป็นวิทยากร แต่สิ่งที่เราได้มากไปกว่านั้นคือ คนที่เราไปพูด เขาเข้าใจ ผู้ติดตามมากขึ้น มีการแลกเปลี่ยนความคิดเห็น ... หนูรู้สึกว่ คนเรามีใช้จะมีแต่คนที่เขารังเกียจ ถ้าเราได้มีการพูดคุย มนุษย์สามารถเข้าใจกันได้ การเป็นวิทยากรให้คำตอบหนูหลายอย่าง เราได้คำตอบว่าเราจะอยู่อย่างไรในขณะที่เรามีเชื้อ ทำให้หนูเข้าใจคน ให้คนอื่นเข้าใจหนู (2/1: p36, 11-26) ... ช่วงที่ออกวิทยากร หนูโชคดีที่ได้เจอคนดีๆ หลายคน เป็นหมอ เป็นนักข่าว ... บางทีเค้าเป็นคนจัดงาน บางทีก็เป็นวิทยากรด้วยกัน แล้วเรารู้สึกประทับใจ คุยกัน โทกคุยกัน มีอะไรก็ปรึกษาทีละที เค้าก็อยากช่วย ให้คำแนะนำได้หลายอย่าง (2/2: p3, 26-29)

These participants always developed themselves under the systematic working procedure and learned about themselves. Furthermore, they had learned about the others, about how to work, as well as about HIV/AIDS by working with HIV-infected people and AIDS patients.

Working hard

The participants worked hard because they knew that their time was limited. They intended to make the most out of the rest of their for both themselves and those whom they loved such as parents or children. Some participants intended to rely on themselves and save money for their treatment expenses. Some participants developed their business and made it become renowned in the community, so they could earn money for both their family and relatives. For example, a 30-year-old male participant had kept his HIV status a secret since he knew the diagnosis. He intended to help his parents as much as he could during the rest of his life as he shared in his statement.

I thought of the four or five years I had left then I would help my parents with my whole spirit till I had a fishing pond... It was a very big fishing park in my province. So my parents and siblings could come to stay with me. I was very proud that I could be responsible for my family... Formerly I begged some money from my parents to hire the workmen to dig a pond. After the pond was finished, I fed some fish. I owned a car, so I went to the market to find some leftover vegetables as fish food. When my business became successful, I asked my parents to live with me. Now I got the respect, so I didn't think of anything. (14/1: p4, 21 – p5, 4)

ผมคิดว่า เวลาที่เหลือ มันจะอยู่อีก 4-5 ปีเนี่ย ผมจะช่วยพ่อแม่ทำเต็มที่ ทำจนผมไปเปิดบ่อปลา... ที่จัดว่าใหญ่ติดอันดับในจังหวัด ทำให้พ่อแม่และน้องๆ ย้ายมาอยู่กับผมได้ทุกคน ผมก็ภูมิใจว่าผมเลี้ยงครอบครัวได้แล้ว ... เดิมทีผมก็ขอเงินพ่อแม่ก่อนนึ่งเพื่อไปจ้างรถมาชุดทำบ่อ พอทำบ่อทำอะไรเสร็จ ผมก็ลงปลา ที่นี้มีรถคันนี้ ผมก็เริ่มหาเก็บเศษอาหารมั่ง หาเก็บใบผักตามตลาดที่เขาฆ่าทิ้ง จนมันได้ผล ก็เลยชวนพ่อกับแม่ไปอยู่ เดี่ยวนี้ก็มีหน้ามีตาขึ้นมา ผมก็ไม่คิดอะไรเลย (14/1: p4, 21 – p5, 4)

Another participant, a father of two sons, developed his business and worked hard for his children until his sons graduated. This can be seen in his quotation:

At that time, I didn't have enough money to send my children to school... My job was not stable. Children were so young. However, I tried to pay for their studies until the university level... During that period, I worked very hard from the morning until one or two in the morning of the next day. (13/1: p3, 31 – p4, 19)

ตอนนั้นเรายังไม่ค่อยมีเงินที่จะส่งลูกเรียน ... งานยังไม่ค่อยมั่นคง ลูกก็ยังเล็ก ก็พยายามดิ้นรนหาเงินให้ลูกเรียนหนังสือถึงชั้นมหาวิทยาลัย ... ช่วงนั้นผมทำงานหนัก ทำงานตั้งแต่เช้า ถึงตีหนึ่ง ติสองทุกวัน (13/1: p3, 31 – p4, 19)

These participants worked so hard that they would keep their mind away from being occupied with the thought about HIV infection. Their works, either for themselves or for their family or for others, would make them proud of themselves. They felt they were still worthwhile, so they were satisfied with their life. In this research, there were only two or three participants who had a stable occupation before they got HIV infection. Their socio-economic statuses were at a middle-class, and they lived with their family. These participants worked as usual, and those who had family also took care of their own family.

Learning about HIV/AIDS

During the stage of fighting for existence, the participants had learned more about HIV/AIDS. They learned about the nature of HIV/AIDS, the factors affecting health and the disease progression, and the appropriate management of the disease. By learning, they developed self-care skills to maintain health or manage the illness. However, some participants did not pay attention to learn about HIV/AIDS in the first few years because they were concerned only about working to support themselves and their families, and thought that they would certainly die within a few years. A few years later, they were still healthy and had a chance to meet other HIV-infected people who had lived for a long period of time. Then, they focused more on how to be healthy and live as long as possible.

The methods of learning included reading books and journals under the subjects of HIV/AIDS, listening to and watching the programs about HIV/AIDS on the radio and television, consulting others who had knowledge and experiences, sharing experiences with other HIV-infected people, searching, observing self and other HIV-infected people, and practicing caring of self and other HIV-infected people. The sources from which the participants learned about the disease might be other healthcare providers and HIV-infected people, the media, and their own experiences with the disease. The participants used many methods and all sources available in learning about HIV/AIDS and they learned in all aspects. They learned more and more, and this led to gradual changes in their perceptions about HIV/AIDS.

Learning about the nature of HIV/AIDS

All participants had learned and known that HIV weakened their immune system, so they could be infected with other microorganisms easily. These opportunistic infections were the causes of HIV-infected people's death. However, these diseases could be prevented and cured and they could take care of themselves to prolong their life. The participants learned these things from many sources. Some participants learned from their experiences in providing care to AIDS patients, as well as reading books and journals. Some participants learned from their HIV-infected friends' experiences with the disease, and others learned from their own experiences. Such learning resulted in a great change of their perception about HIV infection and AIDS. The following statements are some examples of the participant's accounts narrating their learning of the nature of the disease and the change in their perception about HIV infection or AIDS:

I collected documents, news, and my own experiences with AIDS patients' problems and then analyzed them... This disease destroyed our immune system, so we had an opportunity to be infected with other germs more easily. AIDS patients died because of another infection. So, how could we protect ourselves from another infection? We had to take best care of our health. That's all! If only we kept on looking after this, we could live longer. (17/1: p6, 7-16)

เอกสาร ข่าวสารต่างๆ ปัญหาที่คนไข้เอ็ดส์เคยเจอ เราคิดแล้วก็เอามาประมวล วิเคราะห์ดูว่า... 'ไอ้โรคนี้มันทำลายภูมิคุ้มกันในตัวเราให้มันบกพร่องไป โอกาสที่ได้รับเชื้อตัวอื่นมีเปอร์เซ็นต์สูง ฉะนั้นปัญหาที่คนไข้เสียชีวิตเนื่องจากได้รับเชื้อตัวอื่นเข้ามา ฉะนั้นเราทำยังไงที่จะป้องกันดูแลตัวเองไม่ให้รับเชื้อตัวอื่นเข้ามา ดูแลสุขภาพร่างกายให้แข็งแรงที่สุด จุดนี้แหละ ถ้าเรารักษาจุดนี้ให้ได้เราก็จะมีชีวิตอยู่ได้อีกนาน (17/1: p6, 7-16)

At that time I had seen the advertisement. It was so scared... I had seen my friends' symptom. It was more serious than what was shown the picture in the media. I felt all right because they were still able to talk... But in the picture it was like a dead man... During that time I didn't know that they could recover although they had very severe sickness like that... How thin they were! Just like a ghost lying on the bed... I didn't learn that yet. Afterwards I knew that infection didn't mean that my immunity would gradually decrease and I would die. Not at all! There was a chance to recover... Even when getting T.B. or another sickness, we were still able to regain our health. These diseases also occurred to the others, but it was more difficult for us to recover than the others. So, I had to observe myself. (2/1: p43, 23 – p44, 2)

ตอนนั้นเราเห็นภาพสื่อออกมามันน่ากลัว ... หนูเห็นเพื่อนๆ เป็นยิ่งกว่ารูปในสื่อ หนูรู้สึกเฉยๆ เพราะว่าเขาพูดคุยได้ ... พออยู่ในรูปมันเหมือนคนที่ตายไปแล้ว ตอนนั้นก็ไม่รู้ว่าเป็นหนักๆ อย่างนั้น ผอมแห้งเป็นไม้เสียบผี นอนอยู่กับที่นอน ยังฟื้นขึ้นมาได้ เรายังไม่ได้เรียนรู้ตรงนั้น พอเรารู้ว่าการติดเชื้อมันไม่ใช่ว่ามันจะทำให้ภูมิคุ้มกันของเราถดถอยลงไปเรื่อยๆ เรื่อยๆ แล้วก็ตาย มันไม่

ใช่ มันมีโอกาที่จะฟื้น ... เป็นวันโรคก็หายได้ เป็นอะไรก็หายได้ เพราะโรคที่เราเป็นมันก็คือโรคที่เป็นเป็นกัน เพียงแต่จะหายยากกว่าคนอื่น เราก็ต้องสังเกตตัวเอง (2/1: p43, 23 – p44, 2)

Learning about the factors affecting health and the disease progression

The participants had learned that depression and discouragement affected health and expedited the disease progression, whereas joyful feeling and morale were important factors in maintaining health. They learned from reading books and observing other infected people. Such learning was shown in some participants' statements:

I had heard that the CD₄ would increase if we were cheerful and joyous. There would be a substance produced to increase CD₄. However, if we were sad or discouraged or worried, the CD₄ would be decreasing. So, I thought I was still alive. I must make myself get well. I had no time to be in sorrow. I must regain my health. If still getting stuck right there, I would die with them. Here, last year there was the first friend's death and the others in the group were very sad. Previously there were full of laughter right here. Everyone dearly loved each other. But when the first person died, there was another death each month till there were only two still alive. It was a depressing condition that we couldn't regain our health as fast as we should. This disease was up to our mind power. If we were discouraged, the risk to die was instantly higher. (12/2: p5, 12-27)

ผมรู้อย่างหนึ่งว่า CD₄ มันจะเพิ่มขึ้นก็ต่อเมื่อ เรามีอารมณ์ที่แจ่มใส ที่สนุกสนาน มันจะมีสารตัวหนึ่งที่หลั่งออกมา ทำให้ CD₄ เพิ่มขึ้น แต่ถ้าเกิดเวลาที่เรเศร้าใจ หรือท้อแท้ใจ คิด วิตกกังวล ตัว CD₄ จะลดลง ผมก็คิดว่า เรายังมีชีวิตอยู่ เราต้องทำให้สุขภาพดีขึ้น เราไม่มีโอกาสที่จะมานั่งเสียใจมาก เราต้องรีบฟื้นตัวเองให้ได้ ถ้าเราแว่แต่จมปลักตรงนั้น เราก็ต้องไปพร้อมกับเขา เหมือนที่นั่นเมื่อปีที่แล้ว เพื่อนคนแรกตายไป เพื่อนในกลุ่มเสียใจกันมาก เมื่อก่อนนี้มีแต่เสียงหัวเราะ ทุกคนรักกัน พอคนแรกเสียชีวิต ตั้งแต่นั้นเสียชีวิตเดือนละคน เดือนละคน กระทั่งเหลือกันแค่ 2 คน นี่ก็ภาวะที่เสียใจแล้วไม่สามารถฟื้นตัวขึ้นมาให้เร็วที่สุด โรคนี้อยู่ที่จิตใจ ถ้าเมื่อเราท้อ มีโอกาสที่จะไปทันที (12/2: p5, 12-22)

I had studied a lot of information and looked at the conditions of AIDS patients that I used to take care of. I thought that discouragement made symptoms worsened. Mind power was the most important matter to support self. If we lacked courage, the sickness would make ourselves worsened more and more. (17/2: p2, 33 – p3, 4)

ผมศึกษาข้อมูล และดูจากสภาพคนไข้ที่เราดูแลผ่านมา พอท้อแท้ ทำให้โรคกำเริบ กำลังใจเป็นสิ่งที่สำคัญที่สุด ทำให้เราสามารถประคองตัวเองได้ ถ้าหมดกำลังใจ มันก็ยิ่งจะซ้ำเติมเรา สภาพร่างกายก็จะยิ่งทรุดโทรม (17/2: p2, 33 – p3, 2)

All participants knew that CD₄ level reflected the body's immune status and it was an indicator of disease progression. As a consequence, they tried to observe the relationship between CD₄ level and their conditions. They observed not

only what happened to themselves but also to their HIV-infected friends. They learned that the CD₄ level might increase though they did not take any ARV. It was mostly related to the mental state. If they were in a good mental state, namely calmness, no tension, cheerfulness, or pleasant feeling, the CD₄ level would increase. On the other hand, if they were in a state of sorrow, discouragement, and high anxiety, the CD₄ level would decrease. They also observed that the CD₄ level was related to the physical health and some life events. When they had regular exercise, adequate diet, and weight gain, the CD₄ level would increase, while some physical problems and weight loss would decrease the CD₄ level. One participant made a comment that she had a high CD₄ level when she had a job with adequate income, but it was low when she lost the job and faced with a hardship. The following accounts reflect two participants' learning about factors relating to CD₄ level:

After my spouse's death, I had cellulitis. At that moment my CD₄ decreased to around 200. I didn't receive ARV drug. Perhaps it was the period of my adjustment or I had a complication, so my immunity decreased. I took the cloxacillin, performed self-care, and had nutritious food. I tried to relax and forget it...and did exercise as usual. Then it became better...I became well. My CD₄ started to increase...reaching [the level of] 500, then 700 and eventually up to 1000 without taking antiviral drug... Then my health was fine and my weight increased... That period I usually did exercise, so I could eat more... I slept well without any strain. My body took an absolutely rest. (17/1: p3, 24 – p4, 6)

หลังจากแฟนเสียชีวิต ผมเป็น cellulitis คราวนี้ CD₄ เริ่มลงเหลือ 200 กว่า แต่ช่วงนั้นผมยังไม่ได้รับยาต้านไวรัส มันอาจจะเป็นเพราะว่า ช่วงระยะเวลานั้นปรับตัว หรือว่าสภาพเราถูกโรคแทรกซ้อน มันทำให้ภูมิเราลดลงไปได้ ก็ทานยาปฏิชีวนะฆ่าเชื้อ cloxacillin ... ดูแลตนเอง รับประทานอาหาร พยายามไม่เครียด ไม่คิดมัน แล้วก็พยายามออกกำลังกายตามปกติ มันก็ดีขึ้น ดีขึ้น แล้วก็ CD₄ มันก็ขึ้นๆๆ ขึ้นมาเป็น 500 700 แล้วมาเป็น 1000 กว่า โดยไม่ได้กินยาต้าน ... แล้วก็สุขภาพดี น้ำหนักก็ขึ้น ... ช่วงนั้นผมออกกำลังกายเต็มที่ ทำให้เจริญอาหาร ทานได้เยอะ นอนหลับ ไม่เครียด ไม่ฟุ้งซ่าน ร่างกายได้พักผ่อน (17/1: p3, 24 – p4, 6)

I was rather lucky that I had no symptom because my CD₄ level was very high. The first level was around 1340. Two years later, my CD₄ level reached 1600. It was increasing and nowadays I had got the level of 422 left. I thought it was up to my mental status. The mental status was really more important than other matters. Taking care of health was a factor that I always looked after. When we felt upset and worried, certainly it would affect us. But I worked like this... I could help people, so I felt happy. (16/1: p17, 27 – p18, 3)

ผมค่อนข้างจะโชคดี ผมไม่เป็นอะไรเลย เพราะว่า CD₄ ผมสูงมาก ครั้งแรก 1340 อยู่มาประมาณ 2 ปี CD₄ ผมกระโดดขึ้นมาถึง 1600 มันขึ้นๆไป ซึ่งปัจจุบันนี้ ผมยังเหลือ 422 อยู่เลย ซึ่งผมคิดว่ามันเป็นเพราะสภาพจิตใจ สภาพจิตใจสำคัญกว่าอย่างอื่นมากจริงๆ การดูแลสุขภาพเป็นองค์

ประกอบ เราดูแลอยู่แล้ว ถ้าใจเราหงุดหงิด ไม่สบายใจ ครุ่นคิด หมกมุ่น แน่นนอนมันวุ่น ... แต่ว่า
ผมทำงานตรงนี้ ผมได้ช่วยคน มันจะมีความสุข (16/1: p17, 27 – p18, 3)

Learning about the management of the disease

All participants had learned how to manage the disease. They learned what diseases could possibly occur to them, what symptoms they should observe for themselves, and how to take care of their health. They also learned about the therapy including anti-retroviral therapy and its side effects, medical treatment of HIV-related diseases, complementary therapy to increase their immunity and prevent the drugs' side effects. All sources and all methods of learning were used in these learning.

Many participants received the western medical treatment and learned about healthcare from physicians and healthcare providers and they tried to follow it. However, some of them hesitated to take anti-retroviral (ARV) drugs as prescribed by the physicians. They sought more information about the drugs and learned how the drugs worked from their friends who used to take them. They gathered the information and thought about them thoroughly before making a decision whether they should take the ARV drugs, as stated by a participant as follows:

The doctor gave me a bottle of AZT drug during the research project. It said that AIDS was incurable, wasn't it? So, I doubted what the drug was. I started searching for more information. Finally it was just the anti-viral drug, not the cure... And if there were any side effects, my health would become worse since my body needed a lot of energy to resist the drug's side effects. So, I decided not to take it. I'd better take care of my health. I was lucky that I didn't take this drug at that time. Ten years had passed by and the research announced the result that using only AZT drug was ineffective...even taking two kinds of drugs was still ineffective. Right now we must take three kinds... I tried to search for information by reading documents and talking with friends... Just like "How about taking this kind of drug? Getting better?" (12/2: p6, 27 – p7, 6)

หมอให้ AZT มาหนึ่งกระปุก ช่วงนั้นเป็นโครงการวิจัย ผมก็ เอ๊ะ โหนข้อมูลบอกว่าเอดส์รักษาไม่หาย แล้วยานี้คืออะไร ผมก็เริ่มศึกษาหาข้อมูล ผลสุดท้ายมันเป็นแค่ยาต้านเฉยๆ ไม่ใช่ยารักษา ... แล้วถ้าเกิดผลข้างเคียงขึ้น ร่างกายเราก็จะทรุดโทรมไปด้วย เพราะร่างกายเราต้องใช้พลังงานที่จะต่อต้านผลข้างเคียงของยา ผมเลยตัดสินใจว่าไม่กินดีกว่า เราสู้ดูแลสุขภาพดีกว่า ผมโชคดีที่ ณ วันนั้นผมตัดสินใจไม่กินยาดังนี้ ระยะเวลาผ่านมาเกือบ 10 ปีแล้วเนี่ย ผลการวิจัยสรุปออกมาว่า AZT ตัวเดียวไม่ได้ผล ต้องกิน 2 ตัวก็ไม่ได้ผล จนกระทั่งถึงทุกวันนี้ต้อง 3 ตัว ... ผมพยายามหาข้อมูลจากเอกสาร และพูดคุยกับเพื่อนว่า คุณกินแล้วเป็นยังไง คุณกินแล้วดีขึ้นมั๊ย (12/2: p6, 27 – p7, 6)

Some participants complied with the medical treatment and received the ARV drug. They learned the complications of the ARV drug and also

studied about complementary therapy to prevent the complications and take care of their health. They studied about herbal medicine or vitamins and took them in addition to the modern medicine.

One participant knew about his HIV infection since 1986. He and his mother had started studying about vitamin since then. He had learned from textbooks and the Internet. Moreover, he had continuously taken many kinds of vitamin in order to enrich the body's immunity since the first time he knew about his infection. He had started taking an ARV drug since the year 2000. Therefore, he studied the side effects of ARV drug and took vitamin supplement in order to prevent the complications caused by ARV drug. He said:

I knew more about ARV drug. Since taking the drug I had no complication. My immunity was increasing while viral cells in my blood were rapidly decreasing... I still had to take vitamins because ARV drug was a chemical substance. It was a must to take vitamins with it. Due to its side effect such as beriberi or peripheral neuritis, I took vitamin B so that I could avoid these symptoms. (19/2: p2, 28–p3, 1)

ยาต้านต่างๆ เราจู้จุกมันมากขึ้นกว่าแต่ก่อน ตั้งแต่กินยามาก็ไม่มีโรคแทรกอะไร แล้วภูมิคุ้มกันก็เริ่มขึ้น จำนวนไวรัสในเลือดก็ลดลงอย่างรวดเร็ว...แต่ก็ต้องกินวิตามินอยู่ เพราะยาต้านก็เป็นสารเคมี เราจำเป็นต้องกินวิตามิน ผลข้างเคียงของมันอย่างหนึ่งหา ปลาขี้สาทอีกเสกอย่างนี้เราก็ต้องกินวิตามินบีเข้าไป เพื่อที่จะช่วยมันไม่ให้เกิดอาการเหล่านี้ขึ้น (19/2: p2, 28 – p3, 1)

Another participant was interested in studying herbal medicine and tried to have it as much as he could, as he said:

I had read books about each herb's indication... what kind of herb could easily be found around my village... About foodstuff like sweet-sour soup which included chilly, mushroom, and onion... I tried to eat it. I knew it could lift up my health. Sometimes I had some garlic. I must study it by myself. I had bought many books for self-study. (10/1: p7, 17-21)

เราไปดูสมุดสมุนไพร สมุนไพรนี่แก้อะไร ที่หาง่ายๆรอบบ้าน ... อาหารอย่างแกงรวม มีทั้งพริก เห็ด หอม...ก็กิน รู้ว่ามันรักษา บางครั้งเราก็กินกระเทียม ต้องศึกษาเอง ซื้อมือหนังสืออ่านเอง (10/1: p7, 17-21)

Some participants had faced the severe illness but could recover, so they learned from their own experience. However, some participants who were never ill from the opportunistic infection had learned by self-study and from other AIDS patients' experiences. This acknowledgement taught them how they would live with HIV. They would learn what sickness could possibly occur to them, how to observe the symptoms, and how to look after their health. A female participant said the following:

I knew what diseases would easily happen to me, so I observed and took care of myself. If it really happened, I would know how to cure and take care of myself... This made me not scared. (2/2: p11, 4-8)

เรารู้ว่าโรคที่มันเกิดกับเราได้ง่าย ๆ มันมีอะไร แล้วเราก็คอยสังเกตดูแล แล้วถ้าเป็นขึ้นมาจริงๆ เราก็รู้ว่าเราจะรักษาตัวเองยังไง ... มันทำให้เราไม่กลัว (2/2: p11, 4-8)

A male participant knew that he was infected since 1985. He got the severe sickness, which others thought he would die from in 1993. However, he could recover a year later. After his recovery, he said he had learned and known well about HIV. He said:

Frankly I could say I already knew it. I knew about this virus very well. (21/1: p22, 21-22)

ผมพูดได้เต็มปากว่า ผมรู้จักเค้าแล้ว ผมรู้จักไวรัสตัวนี้ดีแล้ว (21/1: p22, 21-22)

He had spent almost ten years on learning about HIV. He had learned through his direct experience of being infected, and got to know how to take care of himself. Afterwards he was able to overcome the severe opportunistic infection. When the researcher asked him, “What does it mean that you know this virus well?,” he explained:

It meant I understood about its cycle. Whenever my body felt exhausted, it certainly attacked me. Right now it was hiding inside me and waiting. If I ignored looking after myself, it would suddenly attack me. (21/2: p4, 18-21)

หมายความว่าเราเข้าใจถึงการดำเนิน วัฏจักรของเค้าแล้วว่า ถ้าร่างกายเราอ่อนเพลียเมื่อไร แน่นอน เค้าจะโจมตีเราแน่ ตอนนี้เค้าซ่อนอยู่ในตัวเรา แต่วันใดที่เรารู้สึกจากการดูแลตัวเอง เค้าจะโจมตีเราเลย (21/2: p4, 18-21)

His knowledge about HIV/AIDS integrated the nature of the disease, the factors affecting health, and the management of the disease. He explained more about what he learned as follows:

This virus makes my immune system become worse. However, it has already been in my body, and I can activate my body to keep up the immunity. It [HIV] would like to be with me, so let it be. The food I have eaten is for both the virus and myself. ...I immediately see the doctor if there is something wrong with my health... If I let the sickness prolong...everything would get worse and worse... I have already put up with it. That's O.K... I used to get well from catching a cold in 7-8 days after taking drug. But now I have this virus...even 2 weeks after taking drug I'm not fine. I would still take the drug. At the same time, my heart also fights against it. I'm not worried and don't care about it... If I felt worried about the sickness, certainly my health would become worse. I would be sleepless and bored with food because of worrisome. (21/2: p3, 18 – 29)

ไวรัสตัวนี้ทำให้ภูมิคุ้มกันเราบกพร่อง แต่เมื่อมันเข้าไปอยู่ในตัวเราแล้ว เราสามารถกระตุ้นตัวเราไม่ให้ภูมิเราบกพร่องได้ จะอยู่กับมันก็อยู่ มันกินมันก็กินเพื่อเธอ[HIV]แหละ ... มีอาการอะไรที่

ผิดปกติในร่างกาย ผมจะรีบรักษาเลย ... ถ้าปล่อยให้อัปเดต ... จะเป็นอะไรที่มันแย่ลงไป ... ขณะเดียวกันเราก็ทำใจว่า OK เราเป็นหวัดสมัยก่อนเรากินยา 7 วัน 8 วันเราหายแล้ว แต่พอเราเริ่มเชื่อตัวนี้แล้ว 2 อาทิตย์กินยาแล้ว อาจยังไม่รู้สึกดีขึ้นเลย ก็ยังต้องกินยาอยู่ ขณะเดียวกันสภาพจิตใจเราต้องสู้ ไม่กังวล ไม่วิตก ไม่ใส่ใจอะไรกับ HIV แล้วหะ ... ถ้าเราวิตกไปกับการเจ็บไข้ได้ป่วย ... บอกได้เลยว่าแย่ กินก็ไม่อร่อย นอนก็ไม่หลับ (21/2: p3, 18 – 29)

Learning about HIV/AIDS helped the participants reduce their fear and anxiety about health problems. They could look after their health and then believe that they could encounter the future illness. Their HIV/AIDS perception had changed tremendously. This disease could not bring them death easily as they used to think. Although having a serious illness, they could recover.

Managing Health and Illness

Most of the participants looked healthy. However, several of them used to have some minor illnesses or severe illnesses. Only a few participants had an appearance of some symptoms such as skin rashes. They all had to manage their health and illness to maintain their wellness, improve their general health, or recover from their illness. Managing health and illness could be categorized into three subcategories that were keeping well, seeking healthcare, and managing the physical illness.

Keeping well

During the period in which the participants were well, they would perform actions to maintain their wellness and improve their general health. They took care of their physical and mental health. They would monitor their health, exercise regularly, eat healthy food, quit or reduce their alcohol and tobacco consumption, take care of personal hygiene, rest adequately, maintain body weight, have regular health check-ups, and take prophylaxis drug to prevent opportunistic infections when they had a low CD₄ level. In addition, taking these actions to maintain their physical health, they also took some actions to reduce stress and keep up a good mental state. The following are the participants' accounts describing their self-care to keep well:

As for caring of health, we should rest enough and care more about food. We also need exercises. When I felt like I was getting sick, I would make my body fit mostly by exercising... If I slept for eight hours, I'd certainly be fine... My food was mostly vegetables...I try to eat what could lift up my health. For example, now I'm still smoking, so I have to take more vitamin C and drink

more water. During the past ten years, my weight was around 47-49 kg. Before my infection, it was the same... Normally, we have three meals a day, right? I have four or five meals a day, but I didn't get plump. My digestive system is quite well. Everyday at six o'clock in the morning ...I always have bowel movement. (15/1; p10, 26 – p11, 11)

เรื่องการดูแลสุขภาพ ต้องรู้จักพักผ่อน เรื่องอาหารการกิน ออกกำลังกายก็ต้องมี บางที่เราดูโทรมๆ ไป เราก็มีแรงกาย ส่วนมากก็จะออกกำลังกาย ... ถ้าได้นอนเต็มอิ่ม 8 ชั่วโมง รับรองสบาย ... อาหารส่วนมากก็จะผัก ... ก็กินในสิ่งที่มันช่วยให้ อย่างเช่น ตอนนี้อยู่ยังดูบุญหรี ก็กินวิตามินซีเยอะหน่อย กินน้ำเยอะหน่อย นานักผมเนี่ย ผมรู้ตัวมา 10 ปีแล้ว 47 48 49 อยู่ระดับนี้ตลอด ก่อนคิดเชือกน้ำหนักขนาดนี้ ... ปกติกิน 3 มื้อใช้มัย ของผมวันนึง 4-5 มื้อ แต่มันก็ไม่เห็นอ้วน กินยังงี้ก็ไม่อ้วน แล้วผมการขับถ่ายดี ทุกเช้า 6 โมงเช้า...ต้องขึ้นมาถ่ายทุกเช้า (15/1; p10, 26 – p11, 11)

First, stop thinking; second, work hard and do exercise; third, have nutritious food; fourth, live in a place with fresh air; and fifth, take medicine. Nowadays I have eggs and drank milk everyday... I also eat regular food as usual. (13/1: p7, 2-7)

หนึ่งไม่คิด สองทำงานออกแรง ออกกำลังกาย สามอาหารการกินดี สี่อากาศดี ห้ามียากิน การคิดเชือกมันก็น้อยลง ทุกวันนี้ผมกินนม กินไข่ทุกวัน ... อาหารอื่นก็ทานปกติ (13/1: p7, 2-7)

Some participants had found a number of complementary therapies in taking care of health, boosting their immune system, reducing stress, and preventing drug complications. Thai traditional medicine, herbal medicines, vitamin supplement, *cheewajit* food (one branch of macrobiotic, using natural food to improve health or heal some diseases), praying, doing meditation, and practicing their religious rituals were all examples of these. These participants usually used the complementary therapy in addition to the modern medical therapy.

One male participant applied the principles of Thai traditional medicine in monitoring and caring of his health. He believed in its principle which stated that the body was composed of four elements, namely, earth, water, air, and fire. The balance of these four elements resulted in a healthy state. On the contrary, the imbalance of them caused an illness. However, when he had health problems and he could not handle them, he would go to see the modern medical doctor. He discussed how he looked after his health as follows:

We could look after ourselves. Our body consisted of four elements: earth, water, air, and fire. Life should be balanced with these elements. After waking up, we should observe ourselves. If you had enough rest, you would feel fresh after getting up. We also had to have bowel movement every morning. You see, you were still healthy if this activity went on as usual. But if you felt like having a fever. Maybe the weather had just changed or you had not enough rest. First you should find the real cause and try to solve it by yourself. If you couldn't, just see

doctors. In case of too much defecation, the earth element was working too hard and you were losing the water element, so your health was worsened. About the fire element, it was about what you had eaten, about your digestive system, and the metabolism. The average body temperature was 37 degrees. However, if more or less than 37 degrees, you should be more careful. (21/1: p17, 20 – p18, 3)

เราสามารถดูตัวเราได้ ร่างกายเรา ดิน น้ำ ลม ไฟ แกะอะไรอย่างก็ไม่ได้ อ่อนอะไรนิดก็ไม่ได้ ต้องดูความสมดุลของร่างกายเรา เข้าขึ้นมาสำรวจร่างกายจิตใจตัวเอง ตอนเช้าตื่นมาจิตใจเราเบิกบาน ถ้าเราพักผ่อนเต็มที่ เข้ามาเราต้องถ่าย เราสามารถดูตัวเองได้เลย เออเราถ่ายปกตินะ ร่างกายเรายังแข็งแรง แต่ถ้ารู้สึกตัวร้อนวูบวาบ ต้องดูแล้วอากาศเปลี่ยนหรือเปล่า พักผ่อนพอมั้ย ... ต้องหาเหตุให้เจอก่อน ถ้าหาเหตุเจอแล้วรักษาหาย ถ้าไม่เจอจริงๆ ก็หาหมอ ถ้าถ่ายมาก ชาติดินทำงานหนักเกินไปแล้ว สุขุเสีย น้ำมากเกินไป ร่างกายก็ไม่ไหว ธาตุไฟ อาหารที่เรากินเข้าไป ระบบย่อยอาหาร การเผาผลาญอาหาร เข้าไปหล่อเลี้ยงร่างกาย อุณหภูมิร่างกายได้ 37 องศา OK ปกติ แต่ถ้าไม่ได้ 37 องศา มากไป น้อยไป ต้องดูให้ได้ รักษาตัวเองให้เป็น (21/1: p17, 20 – p18, 3)

Several participants believed that taking care of mental health was the most important factor in maintaining their health. They tried to keep up the mental well being when they faced with problems. Many strategies were used, such as releasing tension by ventilation, distraction by doing hobbies and some relaxed activities, *tham jai*, having a sense of humor, praying, doing meditation, just being in the present, keeping busy, and having systematic thought of problem solving. The following are examples of the participants' attempt to take care of their mental health:

The things that supported my mind and made me relaxed were my hobbies. I loved pets and gardening. I did whatever entertained myself... It could reduce my stress. I did many activities so that I would be busy. My mind became released... I had some pets such as birds, dogs, and cats... When I played with them, fed them, or groomed them, I was happy and forgot everything. (17/2: p5, 29 – p6, 3)

สิ่งที่มาช่วย support จิตใจ คลายความเครียด คือ ผมเป็นคนชอบเลี้ยงสัตว์ ปลุกต้นไม้ ทำอะไรที่ทำให้เกิดความเพลิดเพลินแก่ตัวเรา ... มันช่วยบรรเทาความรู้สึกที่เรามีความเครียด คือไม่ให้มีเวลาว่าง มันช่วยให้ใจเราสบาย ... ผมเลี้ยงนก เลี้ยงหมา เลี้ยงแมว ... เวลาอยู่กับพวกมัน ให้อาหารสัตว์ อาบน้ำอาบน้ำทำ ประชมน หมดไปแล้ววันหนึ่ง มันก็เพลิน ก็ลืม ไม่ได้คิดอะไร (17/2: p5, 29 – p6, 3)

Every night I pray...I also do meditation every day before going to bed and after getting up. (21/1: p27, 13-14)

ผมสวดมนต์ทุกคืน ทำสมาธิทุกวันก่อนนอนและตื่นนอน (21/1: p27, 13-14)

Some participants had a sense of humor when they joined HIV-infected groups as mentioned by a male participant as follows:

We had lunch together...went back home together... We talked and laughed and enjoyed life together like crazy. (16/1: p16, 1-2)

เราทานข้าวด้วยกัน กลับบ้านพร้อมกัน คุยกัน หัวเราะกัน เล่นกันทุกวัน แหย่กัน บ้าบอใส่กัน (16/1: p16, 1-2)

Sometimes they saw the serious problem as a joke:

As for some serious problems, we just laughed at them and made them become a joke... So, life would be more pleasant and lively. When facing the unable-to-solve problems, I had to settle myself in the good mood first. (2/1: p38, 19-24)
 บางทีเรื่องที่มันหนักมากๆ เราก็นั่งหัวเราะกับมัน เราก็ทำให้มันเป็นเรื่องตลก ... ชีวิตจะได้สดชื่น มีชีวิตชีวา ถ้าอันไหน แก้ไขไม่ได้ ต้องทำให้ตัวเองอารมณ์ดีไว้ก่อน (2/1: p38, 19-24)

Moreover, 'death' was an issue that they often talked about in a funny way. A male participant gave an example of their talk:

This morning there was a case that had health check-up at another place. He came here for re-checking. I told him I had lived without using drug for ten years... He was surprised how I could live without drugs for such a long ten years. I also said...I wouldn't die unless my death came. I thought the mind was very important. We shouldn't be worried. If we must die, even doing nothing we would die. So we laughed together. Let it be...if I must die. Then we talked about death, almost with laughter. (15/2: p3, 19-26)
 อย่างเมื่อเช้ามีcaseที่ไปตรวจที่อื่น แล้วมาตรวจซ้ำที่นี่ เราก็บอก อย่างผมเนี่ย 10 ปีแล้วยังไม่ต้องกินยา ... เค้าก็บอกว่า 10 ปีแล้วหรือ ทำไมอยู่ได้ ไม่ต้องกินยา ผมก็บอก ... มันไม่ตาย มันก็ไม่ตาย เรื่องจิตใจเนี่ยสำคัญ อย่าไปคิดมาก ถ้ามันจะตาย มันก็ตายเอง แล้วก็หัวเราะกัน เราก็พูดว่า ตายช่วงมัน ปลอ่ยมันตาย เค้าก็หัวเราะ คุยเรื่องตายแล้วส่วนมากจะหัวเราะ (15/2: p3, 19-26)

Another female participant tried to understand what was her problem and thought of problem solving systematically when she felt stressed. And she also shared it with others whom she trusted. She said:

When I felt stressed, I talked to myself and asked myself what I was worried about...why it happened to me. I asked myself what I had already managed with it, whether I could solve it or not...why I was upset...what I could do...If I had choices to solve my problems... The best way for me was to talk with the ones I could trust most in that matter. (2/1: p37, 9-16)
 เวลาเครียดๆ ก็ต้องนั่งคุยกับตัวเองทางความคิดว่า ตอนนี้เรากำลังคิดเรื่องอะไร มีที่ยังไง เราได้ทำอะไรไป เราแก้ไขหรือยัง ... เราเสียใจทำไม เสียใจเพราะอะไร เราทำอะไรได้บ้าง มีทางเลือกอะไรบ้างที่เราทำได้ ... และที่ดีที่สุดสำหรับหนูคือ ได้คุยกับคนที่เราไว้วางใจเขาที่สุดในเรื่องนั้นๆ (2/1: p37, 9-16)

Some participants would identify the problems, solved them, or put them down when it was not the time to deal with them or it could not be solved at that time. One participant said the following:

I would divide my problems into groups. The problems in my works would be separated from my house problems. I had got a lot of problems so I could easily get crazy if I didn't put them down or deal with them. (17/1: p4, 15-21)
 ผมจะแบ่งแยกปัญหาที่เกิดขึ้น ปัญหาตรงนี้ที่บ้าน ครอบครัว ที่ทำงาน เราจะไม่เอามาปะปนกัน ผมมีปัญหาเยอะแยะ ผมอาจจะบ้าถ้าไม่รู้จักราง หรือแก้ปัญหาให้ตัวเอง (17/1: p4, 15-17)

Some participants performed actions to take care of their health quite regularly, while others did them strictly only in the first period and when their health got worse, such as when having weight loss and a drop in CD₄ level. The condition that some participants could not perform the actions to take care of themselves was the time when they had inadequate fundamental factors for living.

Seeking healthcare

Most participants had regular health check-ups, and some had regular monitoring of their immune level. Some participants took ARV and some prophylactic drugs regularly and continuously. They usually went to see the physicians when they had an illness. The participants who had a serious illness sought healthcare by seeking hospitalization. There were two participants who did not stay in the hospital during their serious illness. One was imprisoned. He received care from nurses and sometimes received the remedy from the physician. He was once a veteran, so he had the right to receive the free-of-charge treatment in the military hospitals. He tried hard to ask for the best treatment he could gain with his right. He stated:

There was no medicine [in the prison], so I wrote a letter to the war veteran hospital. The social welfare officials in that war veteran hospital would send the drugs to me. Doctors of the jail, where I was imprisoned told me what kinds of drug I had to take. Thus, I said I had the right to receive a treatment from the war veteran hospital. I asked him to write a prescription so that I would send it then. Actually the prisoners would ask their relatives to buy drug for them. (21/2: p2, 22-28)

ขานนั้น[ในเรือนจำ]ไม่มี ผมก็เลยต้องเขียนมาขอโรงพยาบาลทหารผ่านศึก เจ้าหน้าที่สงเคราะห์โรงพยาบาลทหารผ่านศึกเขาก็เอาไปให้ หมอที่มาดูแลในเรือนจำเค้าช่วยบอกว่า ต้องใช้ยาตัวนี้ ตัวนี้ ผมก็เลยบอกว่าผมมีสิทธิตรงนี้อยู่ ผมต้องใช้ยาอะไร เขียนให้ผมได้มั้ย ผมจะเอาไปส่งยาส่งไป ตามปกติแล้ว ผู้ต้องขังที่อยู่ภายใน ถ้าหมอเขียนใบสั่งยา เขาก็จะเอาให้ญาติไปซื้อ (21/2: p2, 22-28)

Another one was a female participant suffering from bone-ache and difficulty walking. She was so ill that she became very skinny. She thought she would be die soon; thus, she did not want to bother her partner. According to her working experiences with NGOs, she had known many people who worked for AIDS organizations. She, therefore, asked them for help and tried to find a place which provided healthcare for AIDS patients. Eventually she found a temple that offered the

healthcare by a monk, nuns, and public health volunteers. She stayed there until she recovered. She portrayed her story as follows:

I intended to stay at Sang Tam Garden, but it was full of patients. My husband brought me to Prabat Nampoo Temple...but they rejected me... Then we asked my friend's mother...so she took me to the ... temple. At that temple they offered vegetarian food. I stayed there for a month and I could eat nothing. Thus, I had to receive saline solution for a whole month... One day, I had found a person who I used to work for. He went there to visit some AIDS patients. I called him and said I couldn't stay here. I couldn't eat anything. He soothed me and asked whether I would move to the ... temple. It was very far and lacked electricity. I said I could. (8/1: p12, 20 – p14, 7)

ดิฉันตั้งใจจะไปอยู่ที่สวนแสงธรรม แต่ที่นั่นไม่ว่าง เต็ม แฟนก็ไปส่งพระบาทน้ำพุ ... เขาก็ไม่รับ ... ก็เลยไปหาแม่เพื่อน ... เขาพาไปส่งที่วัด... ที่นั่นเขากินมังสะวิรัติ ไปอยู่เดือนเดียวกินข้าวไม่ลง กินข้าวไม่ได้ เล้าเลยให้น้ำเกลือ 1 เดือนเต็มๆ ... วันหนึ่งพี่...ที่เคยทำงานกับเค้า เล้าไปเยี่ยมผู้ป่วย เอคส์ที่วัด ก็ไปเจอพอดี ก็ร้องบอกเค้าว่า หนูไม่อยู่ที่นี่ หนูกินไม่ได้ เล้าก็ปลอบใจ เล้าถามว่าจะไปอยู่วัด...ม๊ย อยู่ไกล ไฟก็ไม่มี ก็บอกเค้าว่า อยู่ได้ (8/1: p12, 20 – p14, 7)

Managing the physical illnesses

All of the participants ever had occasional minor illnesses, which did not require admission into the hospital and they were still able to take care of themselves. The minor illnesses might be related or unrelated to HIV. They might be colds, sinusitis, vaginitis, diarrhea, and skin problems including herpes zoster. One male participant talked about his experiences with the illnesses as follows:

I got herpes and diarrhea... That was OK to stay at home. I could take care of myself since I could walk and have meals by myself. Getting diarrhea took about three days and about two weeks for herpes. It was not too bad to endure. (15/2: p 8, 27–30)

ผมเป็นงูสวัด ท้องเสีย ... นอนป่วยที่บ้านก็พอช่วยตัวเองได้ เดินได้ กินได้ ท้องเสียก็จะประมาณ 3 วัน งูสวัดก็จะประมาณ 2 อาทิตย์ ไม่ถึงขนาดป่วยจนไม่ไหว (15/2: p 8, 27–30)

When the participants got an illness, sometimes they went to see the physicians, but at other times they performed self-care. Some participants had learned how to treat themselves and cure the illness from their own experiences with it or from other people. Then they would manage the illness by themselves and use both modern medicines and complementary therapies such as herbal medicine, praying, and meditation. A male participant got herpes zoster three times and he learned how to cure it. He described how to manage the illness as follows:

When I got herpes, I felt so-so since I knew how to cure it. I would immediately take medicine. I would recover after around two weeks. I had got herpes three times. It occurred on my waist and my hands. Last month I got it on my back. (15/1: p10, 15-17) ... When I got herpes last month, I bought drugs to cure

myself. Formerly, they suggested pounding Saled-Pangpon herb, mixing it with clear liquor beer and applying to our skin. Then I applied all to my skin and picked off a scab. Thus, I got scars. Now I knew that using the whole herbs would cause scars... In fact, I only used its juice... Now I took western medicine and cleaned the sore. I became well. (15/1: p11, 28 – p12, 1)

ตอนที่ฉันงูสวัดก็รู้สึกเฉยๆ แต่ว่าเราจะรู้วิธีรักษาคือรีบหายากิน ประมาณ 2 อาทิตย์ก็หาย งูสวัดนี้ผมเป็นมา 3 ครั้งแล้ว เป็นตรงเอว ตรงมือ แล้วเมื่อเดือนที่แล้วเป็นที่หลัง (15/1: p10, 15-17) ... ตอนที่ฉันงูสวัดเมื่อเดือนที่แล้วผมซื้อยากินเอง รักษาตัวเอง เมื่อก่อนเขาแนะนำให้ใช้ยาสมุนไพร เสดดพังพอน เอามาตำผสมเหล้าขาวทา ทีนี้เราก็กินยาทั้งดำและๆ พอมันแห้งเราก็กินไปแยะ มันก็เลยเป็นแผลเป็น ตอนนี้อยู่แล้ว สมุนไพรเราไม่ใช้แล้ว ใช้แล้วจะเป็นแผลเป็น เขาบอกว่าให้เอาแต่น้ำๆ เอาผ้ากรอง กรองเอาแต่น้ำทา แต่ตอนนี้ผมกินยา และทำความสะอาด ก็หาย (15/1: p11, 28 – p12, 1)

In another example, a female participant had skin lesions. She used herbal medicine and practiced Buddha's teaching to treat her skin. She said:

When I got skin pimples, I used sea holly's juice. I boiled some sea holly and used its juice when I was taking a bath. In addition, I observed the precepts while having skin pimples. I stopped eating meat. I started praying and doing meditation... You see...there was nothing left. (18/1: p8, 21-25)

ระหว่างที่ผิวหนังเป็นตุ่มเนี่ย หนูจะเอาน้ำเหงือกปลาหมอ ดั้นเหงือกปลาหมอ เอามาต้ม แล้วอาบทา แล้วระหว่างที่ขึ้นตุ่มนี้ ถือศีลให้หนัก ไม่กินเนื้อสัตว์เลย สวดมนต์ นั่งสมาธิ ... ดูชิกะ ... ไม่มีอะไรหลงเหลือเลย (18/1: p8, 21-25)

Some participants in this study experienced a serious illness, which was an opportunistic infection, such as cryptococcal meningitis, fungal infection in the middle ear canal, and TB. It took several months for the participants to recover and return to their normal state of health. During the illness, the physical symptoms and also some medical therapies usually resulted in suffering. The participants would take some actions to manage these sufferings. One participant had fungal infection in the middle ear canal and suffered greatly from medical therapy. He used meditation and asked the physician to adjust the treatment to reduce the suffering. He said:

I never suffered like this. I had seen from another friend that it was so chilling [after using drug]. I started doing meditation, when they started the therapy. I did my best. However, I got a severe drug allergy. While receiving the drug...it took about six hours...It was deeply painful in the fifth hour since the saline solution almost went out. The vessel was aching and turned red. It was very torturing. When the treatment time was up, my blood vessel was unable to receive more saline solution... Until the seventh day, I had no good blood vessel left for the saline solution. It was extremely suffering. Getting into the fifth hour, I began shivering...and the nurses brought me four or five blankets. I felt so cold...then I cried and asked the doctor to stop drug infusion. Finally, the doctor gave me the oral medicine. I became better since then. (19/1: p8, 6-33)

ไม่เคยทรمانอย่างนี้มาก่อนเลย เคยเห็นเพื่อนที่เค้าเคยได้ว่ามันหนาวล้น พอเค้าให้ ผมก็เข้าสมาธิ ผมพยายามดีที่สุดในแล้ว แต่ผมแพ้อย่างแรง เพราะช่วงที่ได้ยา ... ต้องให้ประมาณ 6 ชั่วโมง พอชั่วโมงที่ 5 ตอนน้ำเกลือใกล้จะหมด เส้นมันจะปวดไปหมดเลย แล้วมันจะแดงพอง มันจะทรมานมาก พอหมดขวดปั๊บ เส้นก็จะไหม้ แล้วก็ให้ไม่ได้ ... พอวันที่ 7 ก็ไม่เหลือเส้นที่จะให้แล้ว มันทรมานมาก พอจะเข้าชั่วโมงที่ 5 ... มันจะสั่นมากขึ้นเรื่อยๆ พยาบาลเค้าจะยกผ้าห่มมาให้ 4 ผืน 5 ผืน มันจะหนาวมาก ผมก็ร้องไห้ บอกคุณหมอให้หยุด หมอก็เปลี่ยนเป็นยากินให้ ก็ OK ก็ค่อยๆดีขึ้น (19/1: p8, 6-33)

In addition, they would try to care for themselves to recover from the serious illness such as eating more food, trying to ambulate, taking drugs, and doing what the doctor and the nurse told them to. For example, a female participant had lymph node tuberculosis and then had nontuberculous mycobacterial infection. She was unwilling to live, so she refused to take drugs. After her son encouraged her, she tried to do everything for recovery, as stated in her quotation as follows:

I did everything the doctor suggested. When I started taking drugs, I was able to have normal food... Then I tried to walk, though walking was so difficult for me during that time. (20/2: p10, 6-12)

หนูทำทุกอย่างที่หมอแนะนำ พอเริ่มกินยาก็กินอาหารได้...แล้วเริ่มหัดเกาะเดิน ตอนนั้นยังเดินไม่ค่อยได้ (20/2: p10, 6-12)

Keeping up morale

Morale (*Kam lang jai*) meant a state of mental well being that occurred when the participants had a strengthened mind and felt confidence in facing any situations with a sense of purpose in living. Keeping up morale referred to the process in which the participants tried to maintain the strength of their mind, the feeling of confidence, and the sense of purpose in living to prevent them from discouragement while they were going through any tough situation in their life. The process of keeping up morale was continuous and dynamic in nature, and it took place throughout the stage of fighting for existence.

Most of the participants had learned from their experiences that keeping up morale was an important thing to do to maintain their lives. One male participant said:

In my opinion, morale is the most important factor. Without morale, although taking [ARV] drug,...you may not take it. You may think that it was no use living... However, if having morale, everything would be fine. We had to take care of ourselves, too... If we had morale, our mental health would be better as well. Finally everything would become better. I thought this matter was the most important thing... Somehow the morale was better than medicine. Those who

never took (ARV) drug were able to live for more than ten years... With courage and good mental health, they could eat. However, for those who lacked morale, they couldn't eat anything, so their health would become worse. (6/2: p5, 3-14)

ผมคิดว่ากำลังใจเป็นสิ่งสำคัญที่สุดเลยครับ ถ้าไม่มีกำลังใจ ถึงแม้จะได้กินยา(ARV) ... คุณก็ไม่อยากกิน กินไปก็เท่านั้น ... แต่ถ้ามีกำลังใจ อะไรๆมันก็ดี เราก็ดูแลสุขภาพของเราด้วย ... ถ้ากำลังใจดี สุขภาพจิตมันก็ดี อะไรๆก็ดีขึ้นมา ผมว่าสำคัญที่สุด ... เผลออากำลังใจอาจจะดีกว่ายาด้วยซ้ำ คนที่ไม่เคยกินยา(ARV) เขาก็อยู่ได้เป็นสิบกว่าปี ... เขามีกำลังใจ สุขภาพจิตดี ก็กินได้ คนที่กำลังใจแย่ กินข้าวไม่ได้ ร่างกายมันก็แย่ (6/2: p5, 3-14)

They also learned that the feelings of discouragement would deteriorate their health. Consequently, they had to overcome these feelings and build up their morale as soon as possible, as a participant stated:

Our feelings could create and destroy ourselves... The feelings of discouragement and despair...would destroy our health. It would make us shattered. Lively body would be dispirited. Our thought would frustrate our soul, and then we would wait for death... We had to overcome our feelings by creating morale and confidence. (17/2: p8, 8-21)

ความรู้สึกของตัวเองทั้งสร้างและทำลายตนเอง ... ความรู้สึกที่ถอย ท้อแท้ ล้มหวัง ... มันทำลายร่างกายเราเอง ทำให้เราถอย ร่างกายที่กระชับกระเฉงก็ห่อเหี่ยว ท้อแท้ ความคิดความอ่านมันไม่สร้างสรรค์ให้กับตัวเอง คอยคิดอย่างเดียวว่า นับวันว่า จะต้องตาย ... เราต้องเอาชนะความรู้สึกตัวเอง สร้างกำลังใจและความมั่นใจให้กับตัวเอง (17/2: p8, 8-21)

In the stage of fighting for existence, the participants encountered many problems that made them experience great pain, sadness, and discouragement. These problems or life situation included serious illness, difficulties in finding jobs, economics problems, and the death of their significant persons. With these situations, the participants developed their own strategies to keep up their morale. The strategies might be empowering self, thinking of someone or something in their concern, reminding self about their purpose in living, learning from others, and setting a possible goal.

Some participants empowered themselves by frequently reminding themselves or praying that they had to be strong and not to be easily discouraged, that they had to fight and to live, and that they could make it. These participants stated the following:

My morale came from myself. I would make myself confident... I set up myself as a brave man who never surrendered. So, I must keep on this character... I believed in myself that I could overcome it. So let's fight! Don't be discouraged. (17/1: p10, 17 – p11, 3)

กำลังใจของผมมาจากตัวเอง เราสร้างความมั่นใจให้กับตัวเอง ... เราสร้างจุดยืนให้ตัวเองว่า เราเป็นคนเข้มแข็ง ไม่ท้อถอย เราต้องทำตรงนี้ต่อไป ... มีความศรัทธาในตัวเองว่า เราสามารถทำได้ เราต้องต่อสู้ได้ อย่าท้อถอย (17/1: p10, 17 – p11, 3)

I prayed for myself, "Don't give up. I have to survive to take care of my parents who are old." And it became my courage. (6/1: p5, 20-22)

เรานั่งภาวนาว่า "เราต้องสู้นะ เราต้องอยู่ได้ คิดถึงพ่อแม่ที่เราต้องคอยดูแล พ่อแม่ก็แก่แล้ว" ให้กำลังใจตัวเอง (6/1: p5, 20-22)

The latter statement clearly illustrated that the participant not only empowered himself, but he also thought of someone in his concern. Sometimes, when the participants felt tired or discouraged, they would think of someone they love or remind themselves about their purposes in living as could be seen in the following participant's statement:

I have to build up my morale. I look around, then see the others and the one I love most... How would they live without me? I'm worried about not only my children but also my Mom. She is so old. I'm worried about this point, so I cannot surrender to the fate. I still have energy, so I must fight... I have to stand for those whom I love and make them happy... This reason can be my moral support. (17/1: p11, 3-21)

เราจะสร้างกำลังใจ ให้มองคนรอบข้าง บุคคลที่เรารักที่สุด ... ถ้าสิ้นเราไป แล้วเค้าจะอยู่ยังไง ผมก็ไม่ได้ห่วงเฉพาะลูก เพราะแม่ก็แก่แล้ว เราห่วงตรงนี้ เราต้องท้อถอยไม่ได้ สองขาเรามีแรง เราต้องยืนอยู่ให้ได้ เราต้องสู้ ... เราต้องอยู่เพื่อคนที่เรารัก ให้คนที่เรารักมีความสุข ... จุดนี้แหละ คนที่เรารัก สร้างกำลังใจให้กับเราได้ (17/1: p11, 3-21)

Some participants learned that other HIV infected people could live for a long time without getting sick and some people could even recover from a serious illness caused by opportunistic infection. Sometimes the participants saw other people have more trouble and these people still fought with courage. They realized they were in a better situation than these people. Such realization would increase their morale.

Setting a possible goal was another strategy to keep up their morale. When the goal was attained, their morale would increase:

I could build up my courage by setting a goal in my life. When I planned to do something, I just set the goal that wasn't too hard to reach. Then I would feel good when overcoming it. (2/2: p13, 13-15)

หนูค่อยมีกำลังใจที่จะอยู่ก็ตรงที่ว่า ถ้าเราคิดจะทำอะไร เราต้องตั้งไว้ที่มันเป็นไปได้ก่อน ตั้งต่ำๆ ไว้ก่อน เอาให้มันแบบทำให้ได้ แล้วเราก็จะรู้สึกแบบทำได้ (2/2: p13, 13-15)

However, in some conditions, such as the time of serious illness or hardship with limited personal resources, the participants needed moral support from others. People who could give moral support to the participants might be family

members, HIV-infected friends, healthcare providers, NGOs' officials, and those who gave care to them. These people might help the participants gain morale by accepting them, understanding them, encouraging them to realize their self-worth, giving care or help, and giving helpful information. The following statements illustrate examples of moral support the participants received from others:

When I got fungus in my brain, I was desperate. I thought my death would come soon. However, when my parents stood up beside my bed, they said I would be OK. They would do everything for me. If they could die to let me live longer, they would. They only wished I would stop fanciful thinking. Just this word...made me...I must fight. I would never surrender again. My parents gave me a lot of moral support. Even their lives they could give me. (14/1: p11, 14-20)

ตอนที่ผมเป็นเชื้อราขึ้นสมอง ผมท้อ ผมคิดว่าเป็นวันตายของผมแล้ว แต่พ่อแม่มายืนข้างเตียงแล้วบอกว่า ไม่เป็นไรหรอกลูก พ่อแม่จะทำทุกอย่างเลย บอกพ่อแม่ให้ชีวิตยังให้ได้ ให้ตายแทนผมก็ได้ แต่อย่าไปคิดมาก เขาพูดแค่นี้ ก็ทำให้ผม...แบบว่า...ผมต้องสู้ ผมไม่ท้อแท้อีกแล้ว พ่อแม่ให้กำลังใจผมขนาดนี้ ชีวิตเขายังให้ผมได้ (14/1: p11, 14-20)

My friend's mother gave me courage... She knew I was alone, thus, she was very kind to me. I got the moral support from her most. She always taught me... Even when I got worse lately, she paid a taxi fee for me in order to send me to see the doctor since I couldn't walk. (8/2: p6, 32 – p7, 8)

แม่เพื่อนจะให้กำลังใจ ... เขาจะดีด้วยมาก แล้วเขารู้ว่าเราตัวคนเดียว เขายังดีใหญ่เลย ได้กำลังใจตรงนั้นมากที่สุดเลย เขาจะคอยบอกคอยสอน...กระทั่งล่าสุดที่ป่วยเยอะๆ แบบเดินไม่ค่อยไหวแล้ว คุณแม่ก็เหมาแท็กซี่ให้ไปหาคุณหมอ (8/2: p6, 32 – p7, 8)

When the participants could keep up their morale, they would have enough power and confidence to face any situation and then problem-solving would occur.

Concealing/disclosing HIV infection

The majority of the participants had lived with partial disclosure since the previous stage, the stage of pulling oneself together to fight. Some participants' HIV status had been revealed to the family and community since they recently known the diagnosis. Some participants disclosed it to someone whom they trusted or could ask for help. Only one participant did not tell anyone for several years until he had cryptococcal meningitis.

As time went by, the participants' HIV status tended to be disclosed to more people. Some participants were open about it to HIV-infected friends, while others to family members and relatives. Some participants who worked in the HIV-infected groups disclosed their HIV infection to the audience of the educational

institutions and factories when they were invited as speakers. Some participants had an illness and then their infection was revealed to their family, colleagues, and community. Furthermore, some participants decided to disclose it to the public. Only few participants had revealed their infection with just only some family members since the first stage continuing to ten years afterwards, or they might disclose it to a few more persons in the family. These participants had a stable occupation in the community such as being government officials or businessperson, and they had never joined any HIV-infected group activities. However, most of the participants still concealed their infection from some people. Therefore, along the process of fighting for existence, the participants had to conceal their HIV status from some people, even though sometimes they intended to disclose it to others that might be someone important, some groups of people, or the public.

Concealing from some people

Several participants had to conceal their HIV infection from some people. Some participants who took responsibility to support their families would conceal the infection from their family members. Some participants concealed it from colleagues and the community because they were in fear of being disgusted and dealing with the adverse effects on their works and their families. Their concealing strategies included preventing being disclosed by the hospital, behaving normally, taking care of self, and dealing with being suspected to have AIDS.

Preventing being disclosed from the hospital. Several participants avoided going to the hospital in their provinces. They mostly received healthcare from the hospital in another province that was distant from their residence. Some participants used an pseudonym and a fake address when they went to the hospital. One participant who was pregnant had to take an illegal abortion. She chose not to get it in the hospital although the hospital allowed terminating the pregnancy for HIV-infected women because she was afraid that her infection might be revealed to others. In addition, one male participant, who firstly found out that he was HIV-infected from the hospital in his province destroyed his medical record of that hospital. Then he had regular health check-ups at a hospital in Bangkok for more than ten years. He said the following:

I didn't want to get a health check-up in a public hospital in the rural area. The nurses were fond of gossiping. If someone was infected with this disease, everybody would know due to the gossip... I stopped going to that hospital after knowing that my blood test result was positive... I went there again in order to get my file chart and threw it away. That was all... And I didn't go there again. (13/2: p7, 12-20)

ผมไม่อยากไปตรวจโรงพยาบาลรัฐตามบ้านนอกบ้านนา พวกพยาบาลชอบ mouth พอเป็นโรคนี้หน่อย รู้กันไปหมดเลย ... ผมเองผมไปตรวจปัสสาวะ แต่ตรวจรู้ว่าเลือดบวกเท่านั้น ตั้งแต่นั้นไม่ไปตรวจอะไรอีก ... พอเราไปตรวจอีกที เราก็ไปขี้มึนแถมออกมา แล้วเราก็ทิ้ง แล้วไปทำบัตรใหม่ ... ผลตรวจเดิมเราก็ทิ้งไปเลย เป็นบัตรหาย เท่านั้นจบ ถ้าไม่ได้ตรวจอีก ผมก็ไม่เคยไปตรวจที่นั่นอีก (13/2: p7, 12-20)

Behaving normally. The participants who did not share their HIV infection with colleagues and the community tried to have activities with others and act as others did, such as working, eating, drinking, exercising, etc. One participant said:

I didn't tell anyone in my workplace. I had lunch with them as usual because I knew the disease couldn't spread through a spoon. So, I tried to pretend I was a normal person... They drank alcohol and I also drank it, but not much since I knew I was sick. (6/2: p3, 32 – p4, 4)

อยู่ที่ทำงาน ผมก็ไม่ได้บอกใคร กินข้าวก็กินกับเพื่อน ... พยายามไม่แสดงออก กินก็กินปกติ เรารู้ว่ามันไม่ได้ติดจากช้อน เราเลยพยายามกินแบบเหมือนเขา กินกัน ... เหล้าเขากิน เราก็กิน เราเห็นว่าเราเป็นอย่างนี้ ก็กินนิดหน่อย อย่าไปกินมากตามเขา (6/2: p3, 32 – p4, 4)

Taking care of self. The participants who concealed their infection would try to take best care of their health especially maintaining their weight level and curing the illness or symptoms they had as soon as possible. If they had a good health, nobody would notice that they had HIV infection. For instance, a male participant who focused his attention on taking care of his health and still looked healthy said:

I took care of myself like this, so no one knew I was infected. Even those who were HIV-infected still asked me whether I was [HIV infected]. Once I felt amused when I went to ask for a helping fund, about 15,000 Baht, from the government. My friend and I went together, and the officials surprisingly asked me, "You too? Both of you were infected?" (12/1: p17, 20-23)

เราดูแลสุขภาพแบบนี้ ใครเขาก็ไม่รู้ว่าเป็น จนกระทั่งคนที่ติดเชื้อเอชไอวี เขาบอกว่า คุณหรือเป็น(ติดเชื้อHIV) ผมจำอยู่ครั้งนึง ตอนที่ผมไปขอเงินสนับสนุนจากรัฐบาล 15,000 บาท ผมไปกับเพื่อน คุณนี่นะเป็น คุณทั้งสองนั้นนะเป็น (12/1: p17, 20-23)

Dealing with being suspected to have AIDS. Some participants were suspected to have AIDS because their physical symptoms had

become strongly associated with AIDS, such as weight loss and skinny body. Furthermore, they were suspected because they stayed in the hospital. The visitors would have doubt and began gossiping. Some participants stayed cool and pretended they did not care, while others denied the gossips. They also tried to take care of themselves in order to get well and tried to work as usual.

A male participant who disclosed his HIV-status just only to his family was suspected to have AIDS by his colleagues when they came to see him at the hospital as mentioned in his statement as follows:

While staying in the hospital, my colleagues visited me and thought I definitely got HIV because I was so skinny. Moreover, almost all patients in this hospital were AIDS infected. Then they started gossiping. (9/1: p5, 12-14)

พอมานอนที่โรงพยาบาล พวกเพื่อนมาเยี่ยมเขาก็คิดว่าผมติดเชื้อHIVแน่นอน เพราะผม และ ส่วนมากผู้ป่วยที่มาโรงพยาบาลนี่เป็นเอดส์ เพื่อนที่มาเยี่ยมผมที่นั่นก็ไปปล่อยข่าว (9/1: p5, 12-14)

When he recovered from the illness and returned to work, he was suspected to have AIDS. He described how he deal with such suspicion:

My colleagues doubted why I became skinny. The laborers teased me that they had a good drug for me. I pretended to show them I was fine... I knew those who had visited me started gossiping... I tried to take good care of myself. I tried to eat more and more, so my weight increased as usual. Everybody became uncertain whether I was sick. Now I could do everything as usual. I could run. So, they were puzzled and thought they might misunderstand. (9/2: p6, 14-21)

คนที่ทำงานเขาสงสัยว่าหน้าตาผอม คนงานเขาก็แซว หัวหน้ามียาดีเอมัย ผมบอก ผมไม่ได้เจ็บป่วยอะไร ... ผมรู้แล้ว เพื่อนที่มาเยี่ยมผมมันไปปล่อยข่าว ... ผมพยายามรักษาตัว เพิ่มน้ำหนัก กินอย่างเดียว กินอย่างเดียวจนน้ำหนักขึ้นเหมือนปกติ คนเขาก็ชักสงสัยว่าเป็นหรือเปล่า ทุกวันนี้ผมก็ทำอะไรต่ออะไรได้เหมือนคนอื่น วิ่งก็ทำได้ จนดูไม่ออก คนงง คิดว่าเข้าใจผิด (9/2: p6, 14-21)

This participant answered the question asking how he felt when he was suspected to have AIDS:

I wasn't afraid. I just stayed cool and looked after myself. I took care of my health, pretended I was all right, and worked as usual. (9/2: p7, 2-3)

ผมไม่กลัว ทำเฉยๆ พยายามรักษาตัวไว้ รักษาสุขภาพ ทำไม่รู้ไม่ชี้ แล้วทำงานตามปกติ (9/2: p7, 2-3)

Disclosing to others

Some participants disclosed the infection to someone, some groups of people, or to the public. They would tell others when they could accept their HIV infection and they were ready to face the results of the disclosure. They also had some

reasons to disclose their infection, others wanted to know their parents' reaction to their infection. Some participants wanted to prepare their family before they were sick. In telling their parents and families, the participants mostly felt content and got support from the families. A female participant disclosed her HIV status to her mother and relatives after she had been infected for four years. She recollected her experience:

Once my relatives came to my house and we talked about AIDS. They said they were afraid of it. I tried to explain that it wasn't so dangerous as they thought. No need to fear... AIDS could be infected only through blood and sexual intercourse... I asked them what they would do if their children were infected. Amazingly they said they would let doctors kill their children. It was because ...just claimed that it was their mistake... So, I doubted whether my Mom would agree with them. I decided to test Mom's integrity. If she could accept me, it would be OK. But if not, maybe I would lose my Mom... Mom was also in the situation. When she went to her room, I suddenly asked her if she would do like my relatives. Suppose I had been infected. She joked that it was no use because I would surely die some day anyway. So, I told her I was infected. She asked me to stop saying like that. It sounded terrifying. Then, I showed her my health check result... Her face turned pale. I thought she couldn't bear the truth, but she said she was OK. I was still her daughter though I was infected. At that time I felt better... After I heard my Mom said like this, I did not care about anyone else ... I was brave enough to disclose to others that I was infected... I told my relatives I was closed to, and all of them could accept what I was. It seemed like they treated me better. Many cousins accepted and treated me very well. When I wanted to eat something, they tried to offer it to me. My disclosure became an advantage. First I felt anxious to let them know; however, I felt relieved to tell everyone now . (4/1: p7, 25 – p8, 27)

มีครั้งหนึ่งที่ญาติมาหา แล้วคุยกันถึงเรื่องเอดส์ เขาบอกว่าเขากลัว เราก็พยายามจะบอกว่าไม่เห็นต้องกลัวเลย ... มันไม่ได้คิดทางอื่น นอกจากทางเพศสัมพันธ์ และทางเลือดเท่านั้น ... เราก็ถามเขาว่า ถ้าลูกหลานเป็นจะทำยังไง เขาบอก ถ้าเป็นจะบอกให้หมอฉีดยาให้ตายเลย มันอยากไป...ประมาณแบบ...เป็นความผิดที่คิดเชื่อ ... เราก็คิดว่า เอ๊ะ แล้วแม่เราจะคิดอย่างนี้มัย ก็เลยตัดสินใจวัดใจแม่ ถ้าแม่รับได้ก็คือรับได้ ถ้าแม่รับไม่ได้ ก็คือ เราคงต้องเสียแม่ ... วันนั้นแม่ก็อยู่ในเหตุการณ์ที่คุยกันเรื่องนี้ พอแม่ขึ้นไปบนห้องก็เลยถามแม่ว่า ถ้าลูกแม่คิดเชื่อ แม่จะให้หมอฉีดยาให้ตายมัย แม่ก็คิดเล่น แม่ก็บอก ไม่ต้องฉีดยาหรอก เดี่ยวอยู่ที่ตายเอง ก็เลยบอกแม่ว่า หนูคิดเชื่อ แม่ก็บอก พุดไม่ดี พุดเป็นलग อย่าพุดอย่างนี้อีกนะ ก็เลยบอกคิดจริงๆ แล้วก็กลัวไปรับรองแพทย์ให้แม่ดู แม่หน้าซีดหน้าเสียเลย เราคิดในใจว่าแม่จะเป็นไรหรือเปล่า แม่ก็บอก ไม่เป็นไรหรอก คิดเชื่อก็ยังเป็นลูกแม่อยู่ ตอนนั้นก็รู้สึกดีขึ้น พอแม่พุดอย่างนี้แล้ว เราก็ไม่แคร์คนรอบข้างเท่าไร ... ก็อยากจะบอกให้คนอื่นรู้ว่า มันคิดเชื่อนะ ... บอกน้า บอกลูกพี่ลูกน้องที่รักกัน ปรากฏว่าญาติพี่น้องรับได้หมดเลย พอรู้ว่าเรคิดเชื่อ รู้สึกว่าญาติจะดีด้วย หลายคนยอมรับและทำดีกับเรา เวลาเราอยากกินอะไรก็จะหาให้ การบอกว่าเรคิดเชื่อกลับเป็นประโยชน์กับตัวเอง ตอนแรกก็เป็นกังวลกับการที่จะต้องบอกคนอื่น แต่ตอนนี้ตัวเองสบายใจที่จะบอกกับคนอื่น (4/1: p7, 25 – p8, 27)

One female participant who recovered from a serious illness thought that her colleagues and many people in her community knew that she had AIDS. Thus, she decided not to conceal it from everyone in her community.

They had already known it. I didn't want to conceal it, so I just told them frankly. After I was open that I was infected, they rarely talked about this matter. (20/2: p5, 19-21)

เค้ารู้กันแล้ว หนูก็เลยไม่อยากปิดบัง ก็บอกเค้าไปตรงๆ พอเราเปิดเผยว่าเราเป็นโรคนี้ เค้าก็เลยไม่ค่อยพูดอะไร (20/2: p5, 19-21)

The investigator asked what made her heart stronger and made her able to reveal her infection to the community, and she responded:

Perhaps it was because I could survive. Two years ago I was almost dead...but I survived. Thus, I became brave that it wasn't easy to die. If not, I would die since I got worse. My sister always talked to me that if it wasn't my time to die, I wouldn't die. She even prepared my funeral; however, I was still alive till now. Therefore, I must fight for survival. So, I didn't care whatever the others gossiped about me. (20/2: p9, 7-16)

เพราะมันรอดชีวิตมั่งกะ เมื่อสองปีที่ผ่านมา บางทีคนเรานั้นจะเสียชีวิตอยู่แล้ว ... แล้วพอหนูมารอดอย่างนี้ หนูก็เลยเข้มแข็งขึ้นว่า คนเราไม่ใช่ตายกันง่ายๆ ถ้ามันตาย มันตายไปแล้วตอนที่หนูแม่พี่สาวพูดกรอกหูบ่อยๆ ถ้ามันไม่ถึงที่ มันไม่ตายหรอก ดูแกสิ ถึงขนาดจัดอะไรแล้ว [เตรียมงานศพ] แกยังไม่ตาย แกต้องสู้ละ หนูก็เลยสู้ ใครว่าอะไรหนูก็ไม่เท่าไร (20/2: p9, 7-16)

Some participants who worked in an organization of HIV-infected people were invited as speakers to talk about their experiences of having HIV infection to groups of people in order to educate them about HIV/AIDS and make them understand HIV-infected persons. Someone might avoid going to the place near their home because they still concealed the infection from their community, and they were afraid of the adverse effects that may happen to their families. Other participants decided to talk about it not just to only some groups of people but also to the entire public. Some of them had support from their family and friends, which enabled them to have enough strength to disclose it to the public. Other participants had nobody in their family left to be concerned about, so their disclosure to the public did not affect anyone. These participants wanted to educate the society, to reduce discrimination and prejudice in the community, and to help other infected people.

A male participant decided to disclose his HIV status to the public after his children had graduated and reached the legal age. He shared his reason to disclose his HIV status:

I decided to disclose my infection because I just wanted to be a guide for those who had recently been infected. They didn't know what to do with their life and where to go. I just wanted them to know what they would encounter next and how they should plan for their future life. I could be their advisor. (21/2: p8, 21-25)

ที่ผมต้องการเปิดเผยตัวเอง ผมอยากจะทำให้เพื่อนที่เค้าเป็นใหม่ๆ เค้ายังไม่รู้ว่าจะทำยังไง จะเดินไปทางไหน อยากให้เค้ารู้ว่า เค้าต้องเผชิญกับอะไร แล้วเค้าควรจะวางแผนแบบไหน เราอาจจะให้ข้อคิด ให้แนวทางเขา (21/2: p8, 21-25)

With the decision to be open to the society, both HIV-infected and family members must be ready to face many effects. This participant talked about the effects of his disclosure.

After my disclosure, I had to move my house so many times. I was kicked off the rented room about two or three times. When my openness was broadcast, 2 days later I went back home and saw my luggage left by the door. They said if I still lived here, everyone would move from this place. That was the thing I had to prepare myself to face. I must know what would happen next... and I had to talk to my family members. (21/2: p9, 20-27)

ผมเปิดเผยตัว ผมต้องย้ายบ้านตั้งหลายครั้ง โดนไล่ออกจากที่พัก 2-3 ครั้ง ผมเปิดตัวทางโทรทัศน์ อีก 2 วันกลับเข้าบ้าน เค้าขนของออกมาวางไว้หน้าบ้าน ย้ายเลยเพื่อน ถ้านายอยู่ คนในนี้จะย้ายออกหมด นั่นคือสิ่งที่เราต้องเตรียมพร้อม เราต้องรู้เลยว่าอะไรจะเกิดขึ้น ... ผมเองก็ต้องเข้าไปในครอบครัว ไป clear กับพี่น้อง (21/2: p9, 20-27)

Another participant, who had known his HIV infection since 1986, had worked in an organization of HIV-positive people. All of his family members knew his status and supported his work. He used his house as the HIV-infected people's and AIDS patients' help center to give advice and help. He described the effects he and his family endured after his disclosure was broadcast on television as well as how he dealt with the trouble:

When I first opened up, my family members were rejected by others. My younger sister said her friends refused to have meals with her. My aunt said she would be fired... Everyone was shocked and confused for a while. Some asked me to stop my openness, while others asked me to stop allowing AIDS patients to visit our house. However, everybody finally understood me after having a talk. And for sure, all of us had the blood check-up, and their results were negative. It showed that although we had lived together for ten years, it wasn't easy to be infected. It could turn the crisis into the opportunity. Everyone carried the result certificate. Certainly living with an AIDS patient couldn't bring you the infection. The more we worked to make this understood, the more we felt absolutely, 100%, confident... So, they carried a blood certificate when talking about AIDS with another persons. We used to talk about this topic so much that in fact we had done a good job. We were doing right... Our house was a place that HIV-infected persons could ask for suggestion. So, why didn't we go on our activity? Finally, we had the conclusion we would go on... Another big problem

was the fact that my friends didn't want to walk with me, almost all HIV-infected friends. They feared they would also be suspected as HIV infected... But afterwards this situation became better. There were still some friends who were not HIV-infected dared to walk with me. (19/2: p6, 29 – p8, 1)

ตอนที่เปิดตัวครั้งแรก คนในบ้านโดนรังเกียจ เพื่อนน้องไม่ทานข้าวด้วย น่าจะโดนไล่ออกจากงาน ... ก็เลยทำให้ปั่นป่วนไปพักนึง บางคนในบ้านขอให้หยุดเปิดตัว บางคนขอให้หยุดรับคนไข้เอดส์ เข้ามาในบ้าน แต่หลังจากที่เราคุยกัน ปรากฏว่าทุกคนเข้าใจ และเพื่อความสบายใจ ก็ยกคนทั้งบ้าน ไปตรวจเลือดกันหมด ก็negativeหมด ซึ่งให้เห็นว่าเราอยู่กันมา 10 ปีมันไม่คิดจริงๆกับการอยู่ร่วมกัน ก็กลายเป็นเปลี่ยนวิกฤตให้เป็นประโยชน์ ทุกคนก็พากันไปตรวจเลือด ว่าจริงๆการอยู่ร่วมกันมัน ไม่ได้คิด ก็ยังทำงานสร้างความเข้าใจในการอยู่ร่วมกันได้สบายใจ ยิ่งมั่นใจ 100% ... เราก็พักผ่อนเลือด ไปให้ความรู้คนอื่นต่อ แล้วเรามาช่วยกันว่า จริงๆแล้วเรากำลังทำงานนี้ เรากำลังทำบุญ อยู่นะ ทุกคนกำลังทำบุญอยู่ บ้านหลังนี้ก็เป็นที่ทำให้ผู้ติดเชื้อเข้ามาขอคำปรึกษา เราจะไม่ทำต่อ หรือ ทุกคนก็สรุปกันได้ว่า ก็ทำต่อไป ... ปัญหาหนักอีกอย่างคือ เพื่อนไม่เดินด้วยเลย เพื่อนผู้ติดเชื้อแทบทุกคนเลยนะ เล่ากันว่าคนอื่นจะมองว่าเค้าเป็นผู้ติดเชื้อเหมือนกัน ... แต่หลังจากที่ดีขึ้น หลังๆก็มีเพื่อนที่ไม่ติดเชื้อ เค้าก็ยังกล้าเดินกับเรา (19/2: p6, 29 – p8, 1)

However, there were still some good side effects that participant's experienced:

When I went shopping in the department store, other people talked to me or said hi like... "Hey! You're..., right?" Sometimes when I was having lunch, some approached and cheered me up just like "Hang on there! I'd like to pay for this meal for you." ... This kind of situation often occurred. That was great! Still, the bad effect was hard to bear. (19/1: p19, 5-7)

เวลาเดินห้าง ก็จะมีคนทัก คุณ... ไข้มั้ย บางทีนั่งกินข้าว ก็เข้ามาบอกว่า สู้ต่อไปนะ มื้อนี้ผมเลี้ยงเอง ... ก็จะเจอบ่อย อันนี้ด้านดี แต่ด้านไม่ดีนี้หนัก (19/1: p19, 5-7)

Intervening conditions

The conditions that influenced the process of fighting for existence were the problems that the participants encountered, social support, and personal resources and attributes. These conditions influenced all of the five strategies, which were seeking fundamental factors for living, learning about HIV/AIDS, managing health and illness, keeping up morale, and concealing/disclosing HIV infection.

The problems that they encountered such as being monitored by public health officials according to the Act 1985; economic problems; difficulty finding a job; social discrimination and prejudice; the death of significant persons--spouse, children, and closed friends; appearance of symptoms; and a serious illness, resulted in discouragement, great pain, upset, and sadness. With these situations they needed to maintain their mental well being and morale to manage their lives.

Social support was crucial in the time that the participants could not support themselves or they were in a critical situation. They might receive support from

family, friends -- both HIV-infected and non-HIV-infected, colleagues, health center, healthcare professions, both governmental and non-governmental organizations that assisted the HIV-infected persons in need. The support might be giving the fundamental factors for living, caring, and encouraging, or giving moral support. These forms of support could help the participants keep going on with their life and keep up their morale in the difficult times.

Personal resources were something that the participants had and could be drawn upon when needed to support their living. These resources were socio-economic status, education, and vocational skill. The participants who had limited resources needed more support from others than those who had more resources. In addition, some personal attributes such as persistence and fighting spirit seemed to facilitate their strategies in fighting for existence. Some participants persistently asked for help and support till they gained some, though firstly they were rejected. They did not easily feel discouraged while facing with a hardship. Although sometimes they felt discouraged, they could rapidly regain their morale to fight against the difficulties.

Consequences

In order to fight for existence, the participants worked hard so that they could meet their families' and their own basic physical needs for living. Some participants worked to give help to the others, too. Therefore, they were proud of themselves and had a sense of self-worth. Some of them could attain their purposes in living. However, some participants were trying to attain them. To achieve the whole purpose or even some parts of it would make them feel satisfied with life.

Learning about HIV/AIDS could change the participants' perception about HIV infection or AIDS into something positive. Now they perceived that they could live for a long time if they took care of their health. HIV-related diseases could be prevented and cured, and they could recover though they had a serious opportunistic infection. They had developed the competence in managing health and illness. Thus, they had confidence in living with HIV. Fear and anxiety would be decreased. They felt confident that they could confront the sickness caused by HIV afterwards. After facing the problems along this period, they would have the stronger mind and more morale to go on with their life.

In summary, the participants started their fighting for existence with the condition in which they realized their self-worth and the worth of their lives, had a will to live, had a purpose in living, and had morale. They perceived that they could live for many years. These conditions led them to fight for their lives and their family. The participants took many years in this stage, ranging from a few years to over a decade. Their strategies in fighting for existence included seeking fundamental factors for living, learning about HIV/AIDS, managing health and illness, keeping up morale, and concealing/disclosing their HIV-infection. The participants sought the fundamental factors for living by mobilizing resources, finding jobs, and working hard. With these actions, the physical needs of themselves and their families were served. They could support themselves and their families, so it made them feel proud of themselves, have more sense of self-worth, and be satisfied with their lives.

At the end of this stage, their perception about HIV infection or AIDS had changed considerably through their learning and managing their health and illness. They viewed HIV/AIDS in a more positive way. They perceived that they could live for a long time if they took care of their health. The HIV-related diseases could also be cured. They could recover even if they had a severe illness. The participants also developed competence in managing health and illness and felt confident in living with HIV.

Stage 4: Living Normally

The acts the participants performed in fighting for existence in the previous stage gradually constituted a state of living normally. Living normally was a state that the participants perceived themselves and went on with life as ordinary persons in the society. They carried themselves in ways that agreed with social norms and they felt satisfied with their life. For example, a male participant said that in those days he lived his life as other normal people did. He explained what he meant as follows:

I just lived like normal people...like nothing happened...behaved in the same way as other people did...eating, living, and working as usual... I knew what I was [HIV infected] and accepted it. But I didn't think of it all the time... We should be as it used to be...like ordinary people. Don't worried. Just pay attention to it [HIV/AIDS] such as a discovery of a new drug. I was interested in the news like this and kept on track. (10/2: p4, 8 – p5, 2)

เราก็อยู่ตามปกติเหมือนคนทั่วไป เหมือนกับไม่มีเรื่องอะไร ... ดำเนินชีวิตตามปกติอย่างที่คนทุกๆ คนเค้าทำกัน กิน อยู่ ทำงานตามปกติ ... เรารู้ว่าเราเป็น [ติดเชื้อHIV] ยอมรับว่าเป็น แต่ไม่ต้องมานั่งคิดว่าเป็น ... มันต้องทำตามปกติเหมือนคนทั่วไป ... ไม่ต้องกังวลอะไร แต่สนใจเรื่องนี้ [HIV/AIDS] เช่นว่ามียาใหม่ขึ้นมาปั๊บก็สนใจว่า รักษาได้มั้ย ที่เขาวิจัย ต้องติดตาม (10/2: p4, 8 – p5, 2)

Causal conditions

The causal conditions for entering into this stage included perceiving HIV infection or AIDS in a positive way, perceiving themselves and their life as normal people, having competence in managing health and illness, having confidence in living with HIV, and realizing the uncertainty of life. The participants who had lived through this stage had learned a lot about HIV/AIDS, themselves, others, and life. They had developed a competence in management of their health and illness. They felt confident to live with HIV and to confront with the consequences of the disease process. Their perception about HIV infection or AIDS had changed in a positive way. Their perception was an important condition that caused them to live normally just like normal people.

The participants' perception about HIV infection and AIDS in this stage could be divided into four categories: a chronic disease, not a disgusting disease, a company living together, and an opportunity of life.

A chronic disease. The participants viewed HIV infection or AIDS just like a chronic disease. They perceived that HIV infection or AIDS was treatable

but could not be cured. It did not cause them to die early. They could live long by taking care of themselves or taking ARV drugs. Some participants experienced that anti-retroviral (ARV) drugs were able to decrease the viral level and increase their immune status. Moreover, medical treatment could cure the opportunistic infections which were the causes of death. The following are the participants' statements indicating such perception about HIV infection and AIDS.

In fact, catching AIDS doesn't mean you would die soon. It is a chronic disease that can be cured only if you take good care of your health and take drugs. It's just like diabetes or hypertension or another sickness. I think it is less dangerous than cancer. Although you survive from cancer, you don't know whether it will come back. However, getting HIV, we can survive by taking better care of health... just always check up the immune and the viral level. Now medicine is cheaper... so always take it on time. (19/2: p11, 17-23)

จริงๆเอดส์เป็นแล้วมันไม่ได้ตาย มันเป็นโรคเรื้อรังที่รักษาได้ ถ้าดูแลรักษาตัวเอง กินยา มันก็เหมือนเบาหวาน ความดัน เหมือนโรคหลายๆโรค ผมว่ามันยังอันตรายน้อยกว่ามะเร็ง มะเร็งตายก็ตายเลย รอดก็รอดกันไป รอดแล้วยังไม่รู้ว่ามันจะกลับมาอีกเมื่อไหร่ แต่HIV ถ้าเราหันมัน ดูแลระดับภูมิคุ้มกันทานกิน ดูแลงานไวรัสในเลือด ถึงเวลากินยา ก็กินยา เดี๋ยวนี้ยาถูกลงตั้งเยอะแล้ว (19/2: p11, 17-23)

I think I still have an opportunity to further my life. Although there is no drug, I'm still able to take care of myself. (6/2: p1, 5-7)

คิดว่าเรายังมีโอกาสที่จะอยู่ได้นาน ถึงแม้จะยังไม่มียารักษา ก็ยังสามารถปฏิบัติตัว รักษาตัวเองให้ดี (6/2: p1, 5-7)

Drugs from this place are very good. It can kill HIV and also able to control the CD₄ level ... The treatment here is also good. Even fungal infection in the brain can be cured. (9/1: p2, 18-20)

ยาที่นี่ดีมาก สามารถฆ่าเชื้อHIVได้ CD₄สามารถควบคุมได้ ... การรักษาที่นี่ก็ดี ขนาดเชื้อราขึ้นสมองก็รักษาหาย (9/1: p2, 18-20)

Not a disgusting disease. The participants had learned the modes of HIV transmission and knew that it was not easy to transmit to other people. So, the disease was not fearful for other people and they could live with their family and community. Moreover, they saw themselves just as normal people who had an illness. They were not bad or disgusting persons. Such perception is stated in the participants' following accounts:

This disease isn't easy to transmit, so I behave as usual. (6/1: p11, 30-31)

โรคนี้มันไม่ได้ติดง่ายๆ แล้วตัวผมก็ใช้ชีวิตปกติ (6/1: p11, 30-31)

I'm not wrong that I'm AIDS infected. I'm the same one my friends have known... It isn't my fault to be infected. (4/1: p11, 30-31)

เราไม่ได้เป็นคนที่เราว่าที่ต้องติดเชื้อเอดส์ ก็คือเพื่อนคนเดิมที่เรารู้จัก... ไม่ใช่คนที่เราว่าที่ติดเชื้อ (4/1: p8, 16-18)

A company living together. Some participants viewed HIV as a company living with them in their bodies. It always warned them that they had to take good care of themselves and be careful in living. However, they realized that they could die anytime. These participants reflected on their thoughts about HIV:

I think it [HIV] is like something that is part of my life. (2/1: p27, 1-2)

เรารู้สึกว่ามัน[HIV]เป็นอะไรอย่างหนึ่งที่มีส่วนร่วมกับชีวิตเรา (2/1: p27, 1-2)

It is a living thing as our life. But it is a life hiding in our body. If each of us can live individually without causing each other any harm and depending on the other, we can live together peacefully. (17/1: p12, 11-14)

มันเป็นสิ่งมีชีวิตเหมือนชีวิตเรา แต่เป็นชีวิตที่มันแอบแฝงอยู่กับเรา ถ้าต่างคนต่างอยู่ อาศัยพึ่งพาซึ่งกันและกัน อย่าทำลายซึ่งกันและกัน ก็จะอยู่ด้วยกันไป (17/1: p12, 11-14)

I just think that HIV was my friend...who always reminded me to take care of my health and to live my life carefully. (9/2: p3, 5-7)

คิดเสียว่าHIVมันเป็นเพื่อนเรา ... มันเตือนสติเรากับ ต้องรักษาสุขภาพ อย่าประมาท (9/2: p3, 5-7)

An opportunity of life. Some participants perceived that HIV infection or AIDS provided many good opportunities in their lives. Most of the participants were those who had risk behaviors, such as drug addiction, heavy drinking, participation in the nightlife, and promiscuity. Nevertheless these days most of them dedicated themselves to work for others in the AIDS organizations. They thought that the disease made their lives change in a positive way. They changed to be good persons. They were able to quit risk behaviors, make merits, and have a worthwhile life. They had gained many life experiences that they would never have if they were not HIV-infected. They had opportunities to be speakers in several places. Some participants had opportunities to go abroad as representatives of HIV-infected Thai people in the international conference on AIDS, while other participants had a chance to go abroad to visit and learn about AIDS in other countries. Such perceptions are expressed in the following statements:

Before I had HIV infection... I was just a rake... I had nobody and no rule in my life... I did what I wanted to do. After I was infected, I felt first I should take care of myself... I had a chance to work for society. Though where I am now is a small organization, I feel that my life is more valuable compared with the past.

Before the infection I always got drunk and my life was worthless. But nowadays I can help other HIV-infected people. It's quite different. (16/2: p7, 15-27)

ก่อนติดเชื้อHIV...ผมล้มเหลวเลย ... ผมไม่มีใคร ไม่มีกฎเกณฑ์อะไรในชีวิต ... อยากจะทำอะไรเราก็ทำ ตั้งแต่ติดเชื้อมา ทำให้รู้สึกว่าเป็นการรอบคอบ ดูแลสุขภาพตัวเองก่อน ... ทำให้ผมมีโอกาสใช้ชีวิตอยู่ในสังคม ถึงแม้ว่าตรงนี้จะเป็ยแค่องค์กรเล็กๆ แต่ผมว่าชีวิตผมมีคุณค่ากว่าเดิม จากเดิมที่ไม่ได้ติดเชื้อมานี้ ... ผมเมาตัวเอนไปเอนมา ไม่มีคุณค่าอะไรเลยตรงนั้น กับทุกวันนี้ที่นั่งอยู่ช่วยเหลือผู้ติดเชื้ออื่น มันผิดกันเยอะมาก (16/2: p7, 15-27)

If I had not been infected, I wouldn't have had a chance like this. Since I have just grade-4 education, I would have got only a low-paid job. After I was infected, I had a good job. I had a chance to stay in marvelous hotels, to have good meals, and to travel by plane. I felt good. It was good to gain such a great experience and many things because of the infection. I could obtain what I hadn't obtained before. (15/1: p12, 25-31)

ถ้าเราไม่ติดเชื้อ เราคงไม่รู้จักโลกภายนอกได้กว้างอย่างนี้ คือทำงานไป เงินก็ยังไม่พอใช้อยู่ดี เพราะความรู้เรา ป.4 หลังจากเราติดเชื้อ เราได้ทำงานอย่างนี้ เรามีโอกาสเข้าโรงแรมหรูๆ ได้กินอาหารดีๆ ได้นั่งเครื่องบิน รู้สึกว่ามันดี สำหรับตัวผมนะ ดีในแง่ที่เราได้ประสบการณ์ ได้อะไรหลายๆอย่างจากการที่เราติดเชื้อ ได้สัมผัสสิ่งที่เราไม่เคยสัมผัส (15/1: p12, 25-31)

Even though I was infected with this disease, I never thought it was a terrible thing. I meant I had gained a lot... I had never been to abroad before, but now I had a chance to go abroad...and many things I had obtained. I feel like it is an opportunity...to make merits. (16/1: p17, 6-10)

ถึงแม้ว่าจะติดเชื้อมานี้ ผมไม่เคยคิดว่ามันจะเป็นสิ่งเลวร้าย คือสิ่งที่ผมได้รับ...ผมไม่เคยไปต่างประเทศผมก็ได้ไป...และหลายๆอย่างที่ผมได้สัมผัสมา ผมมีความรู้สึกว่ามันเป็นโอกาสที่...เค้าให้โอกาสเราทำดี (16/1: p17, 6-10)

Moreover, HIV infection gave them an opportunity to learn a lot about life. The suffering of being HIV-infected persons led them to learn about themselves, others, and the reality of life as mentioned by some participants as follows:

It (HIV infection) is a chance that gave me a lesson on how to live with a disease and other people. I have learned more about other persons, too. Furthermore, it is an obstacle challenges me whether I can overcome it or not. It isn't just only the absolute sickness... It taught me what is the essence of life. (2/1: p41, 27-32)

มัน(การติดเชื้อHIV)เป็นโอกาสอย่างหนึ่งที่ทำให้เราได้บทเรียนที่จะมีชีวิตร่วมกับคนกับโรค ได้เรียนรู้คนอื่นมากขึ้น และมันเป็นอุปสรรคท้าทายด้วยว่า เราจะผ่านช่วงนี้ไปได้ไหม มันไม่ได้มากับความเจ็บป่วยเพียง...มันมาบอกให้เราเรียนรู้ว่า แก่นแท้ของชีวิตเราอยู่ตรงไหน (2/1: p41, 27-32)

I feel like AIDS has changed me to be a better person. If I had not been infected, I wouldn't have had time to look after my Mom. I might enjoy working and spending my time with my friends as other teens. But nothing happened like that now. I feel like my whole time is spent on AIDS and society... It makes me understand more about myself. I have learned more about the real life. I have

learned about sorrow and many things. AIDS made me rely on religion. Therefore, I finally know what the real tranquility is. (19/2: p8, 14-23)

ผมรู้สึกว่เอดส์ทำให้ผมเป็นคนดี เพราะถ้าไม่ได้เป็นก็อาจจะไม่ได้ดูแลแม่ อาจจะทำงานปกติ แล้วก็ไปเที่ยวกับเพื่อนตามประสาวัยรุ่น แต่ว่าตรงนี้นั้นไม่ใช่ เวลาทั้งหมดของเรานั้นแทบจะให้เอดส์ ให้กับสังคม...มันทำให้เราได้รู้จักตัวเราเอง รู้จักชีวิตจริงๆ รู้จักความทุกข์ รู้จักอะไรอีกเยอะแยะมากมาย ทำให้เราได้เข้ามาหาทางพระ ทำให้เราได้รู้ว่าอะไรคือความสงบที่แท้จริง (19/2: p8, 14-23)

The participants' perception of self and life was also another condition that led them to move into the state of living normally. They perceived that they were not different from other normal people. They were just people with the infection in the body. They had potential and had a living like other people. They stated:

Infected people are just the ordinary persons with the disease inside them. (3/1: p14, 10)

คนติดเชื้อก็คือคนธรรมดาที่มีเชื้ออยู่ในร่างกาย (3/1: p14, 10)

My life now is like normal people's life, like I was not infected. That is because I have a job and I'm still healthy. So, I think my life is the same as other normal people's life. (12/1: p18, 8-10)

ชีวิตตอนนี้มันเหมือนคนปกติแล้ว เหมือนคนไม่มีเชื้อแล้ว เพราะหนึ่งเรามีงานทำแล้ว สองสุขภาพเรายังแข็งแรงดี ผมก็มองว่าผมมีชีวิตเหมือนคนปกติทั่วไป (12/1: p18, 8-10)

They realized self-worth to their family, other people, and the community. The participants at this stage aimed at being healthy; living as long as possible in order to take care of or support their children, grandchildren, parents; and also being helpful to other HIV-infected people and community. Some participants defined their aim and intention as follows:

What should I do in order to live long? What could I do to prevent my health from worsening? While I was still alive, what could I do for society, at least for my family?... What could I do to make the ones I love and care be happy? (17/1: p7, 32 – p8, 3)

ทำยังไงเราจึงจะมีชีวิตยืนยาวต่อไปได้ ทำยังไงไม่ให้ร่างกายเราทรุดลงไปกว่านี้ ทำยังไงช่วงที่เรามีชีวิต มีเวลาอยู่ เราทำคุณประโยชน์ให้แก่สังคม อย่างน้อยสังคมของครอบครัวเราเอง ... คนที่เรารัก คนที่เป็นห่วง เราจะทำยังไงให้เค้ามีความสุข (17/1: p7, 32 – p8, 3)

I was finding a new job. My son had got an idea to make the home-made chopsticks for sale. He was interested in this business... He paid attention to my idea such as doing the sweet bamboo-shoots farm or Mae-Khong giant catfish farm. That's OK. He was interested in what I had suggested. Though we couldn't do it right now, it could be his fundamental knowledge... Nowadays I only

wished I could help him as the back-up since I was very old. I would help him manage basic work or contacts. (13/2: p6, 12-21)

ผมกำลังหาเส้นทางทำงานใหม่ ลูกก็มีความคิดของเขา จะทำอะไร ลูกก็สนใจ ... ผมพูดอะไรไป ลูกก็สนใจ จะเลี้ยงปลาบึก...จะขายหน่อไม้หวาน เค้าก็สนใจหมด ก็ดีแล้วแหละ เราพูดอะไรไปแล้วลูกสนใจ ถึงไม่ทำก็เป็นความรู้เบื้องต้น...ตอนนี้ผมคิดว่าจะช่วยลูก ตัวเองไม่ทำแล้ว ต้องให้ลูกเป็นหัวเรี่ยวหัวแรง เรามั่นใจแล้ว จะช่วยดูพื้นฐานเบื้องต้น การติดต่ออะไรต่างๆให้ลูก เราอยู่แค่เบื้องหลัง (13/2: p6, 12-21)

The participants also thought that “death” was something that everybody had to go through. No one could escape it. They realized that lives were uncertain and they could die anytime. Therefore, they prepared themselves to face it with courage. One participant stated:

Although I got worse or must die now, I was ready and would be pleased... Nothing lasted on earth when time was up. (16/1: p15, 5-11)
ตอนนี้ถ้าเป็นอะไร ล้มหมอนนอนเสื่อ ต้องจากโลกนี้ไป หรือจะต้องตาย ผมพร้อม แล้วก็ยินดี...เมื่อถึงเวลาทุกชีวิตก็ต้องจากโลกนี้ไป (16/1: p15, 5-11)

Contextual conditions

The social context at this time had changed a lot. There were so many HIV-infected groups and organizations well established in every region of the country and developed to be a network. These groups and organizations were well known to the community and society and could be easily accessed. Their activities aimed to give support and counseling to HIV-infected people and their family, to create social understanding in living together with the infected people, to protect the rights of HIV-infected people, to develop the abilities of its staff, and to influence the national policy about HIV/AIDS. Thus, these groups and organizations offered the supportive environment for most of the participants. Some participants took part in developing these groups to be a network around the country. A participant, who worked for the network of HIV-infected people of Thailand, stated:

After I had worked in the club for two years, I started the coordination program with other units and managed the network with friends. It made me more convinced that I had done the right thing. We should be alert to develop ourselves... Right now, Chiang Mai, Phuket and other provinces in the Northeast seemed closer to me. They looked nearer compared with the past. My friends lived near me. (1/1: p17, 3-15)

หลังจากผมทำงานในชมรม 2 ปี ก็เริ่มที่จะประสานกับหน่วยงานต่างๆ และเริ่มเรื่องของการเครือข่ายกับเพื่อนๆ มันยังทำให้เรามั่นใจขึ้นเรื่อยๆว่า สิ่งที่เราทำอยู่มันใช่ มันต้องให้พวกเรารุกขึ้นมา ไม่ยอมมือถอย ต้องลุกขึ้นมาทำอะไร ... ตอนนี้ เชียงใหม่ ภูเก็ต อีสาน เรารู้สึกว่ามันใกล้เข้ามานิดเดียว มันไม่รู้สึกไกลเหมือนเมื่อก่อนแล้ว เพื่อนเราอยู่ใกล้ๆแค่นี้เอง (1/1: p17, 3-15)

At the same time, the society had gained more knowledge about HIV infection and AIDS, as well as had reached some understanding of HIV-infected people. Some community accepted the infected persons. Therefore, some participants could live in the community as usual with complete disclosure. However, many people or the majority of people in the society still did not understand the infected people like this. They still discriminated and had prejudice against people with HIV.

Action and interaction strategies

The action and interaction strategies the participants performed in this stage were living together with their family and community, working, living in harmony with HIV, developing a warm family, and preparing self for future illness and death. The following section will describe each of these strategies.

Living together with family and community

In this stage the participants lived together with the community and/or their family just like normal people. Some participants lived with partial secrecy, while others lived with complete disclosure. The participants who lived with partial secrecy had to conceal their infection from some people. The participants who concealed the infection from the families were those who took responsibility in supporting the families' living. Some participants who disclosed the infection to their family gained love and support from the family. They lived normally and happily with their family who had understanding and acceptance as expressed in some participants' statements as follows:

I have to build up the happiness among family members. I must live happily with the present life. Every evening we would have dinner together. My children, my parents, and I would have dinner together every day, like this forever. (14/1: p12, 5-7)

ผมอยู่ต้องทำให้มีความสุขในครอบครัว ผมต้องมีความสุขเหมือนที่ผมเป็นอยู่ ตกเย็นก็กินข้าวพร้อมกัน ลูกเต้า พ่อแม่ ผมจะกินข้าวร่วมกันอย่างนี้ทุกวัน และจะเป็นอย่างนี้ตลอดไป (14/1: p12, 5-7)

I had learned that eventually though we were accepted by everyone else...we couldn't live happily unless we gained understanding from our family, lovers, parents, and relatives... Right now I realized how happy I was because of my family. (2/1: p31, 26 – p32, 2)

เราเรียนรู้ว่า ที่สุดแล้ว ถึงแม้เราจะถูกยอมรับจากใครก็ตาม ... แต่ถ้าเราขาดการยอมรับจากคนในบ้าน จากแฟน จากคนที่บ้าน (พ่อแม่ และญาติพี่น้อง) เราก็ไม่สามารถที่จะมีความสุขได้ ... ตอนนี้เรารู้ว่าชีวิตที่มีอยู่เรามีความสุขยังงี้ในครอบครัว (2/1: p31, 26 – p32, 2)

Some participants who concealed the infection from the community and society could still work in the community and society as usual. They still fulfilled their responsibility in their workplace and joined the activities as usual with colleagues and other people in the community. When they were suspected to have HIV, they would ignore or deny it, behave normally, and try to take care of themselves to look healthy just to make other people get over it.

For the participants who disclosed the infection to the community and society, they could live normally in their communities. They could join activities with villagers as usual and could talk openly about their infection to others. They could really help other HIV-infected people in the village and educate their communities. Most people in the communities accepted them. For example, a female participant revealed her infection to the community and sometimes she talked joyfully about her infection with others as follows:

Formerly when I was teased, I cried alone and felt angry to myself why I had to suffer like this... But now... It became just a joke... Sometimes they teased me like, "Beware of her! AIDS could jump from her to us!" So I replied if it could be spread so easily as they said, I would let it jump from my body to everyone in the village. And we laughed together. (20/2: p8, 23-30)

แต่ก่อนตอนใหม่ๆ พอใครทำอะไร หนูก็มาแอบร้องไห้ โหมตัวเองที่ทำไม่ดั่งเป็นอย่างนี้ ... พอตอนนี้... บางทีเป็นเรื่องตลกไปเลย... บางทีเค้าพูดเล่นว่า "อย่าเข้าไปใกล้ล่ะ เดี่ยวเชื้อมันจะกระโดดใส่ง่าย ๆ" หนูก็ว่า ถ้ากระโดดใส่ง่าย ๆ จะกระโดดใส่ให้หมดเลย หมู่บ้านทั้งหมู่บ้าน เค้าก็หัวเราะกันเฮ (20/2: p8, 23-30)

However, some people in the community were still afraid that they would be infected with the virus from having a meal or talking with her. When she knew that, she did not feel upset anymore, but she tried to explain to those people that infection did not take place easily as stated in her quotation as follows:

Some said they were afraid of being infected by having meals together. They didn't want to talk to me because they were scared of my breath. They didn't talk like this with me, but just talked to the others. I used to ask them ... but they kept their silence. Therefore, I explained that there was no need to fear. This disease was not easily to infect. (20/2: p9, 1-5)

บางคนเค้าพูดว่า ทานอาหารร่วมกัน กลัวติด ไม่อยากคุยด้วย กลัวติดจากลมหายใจ เค้าจะไม่พูดกับเราหรอก เค้าจะพูดกับคนอื่น ต่อหน้าเราเค้าจะไม่พูด เราไปถามเค้า ... เค้าก็เงียบ เรายกอธิบายให้เค้าฟังว่าไม่ต้องกลัวติดหรอก โรคนี้ไม่ใช่ติดง่าย ๆ (20/2: p9, 1-5)

Working

The participants still continued working to support themselves and their families. They were so proud of themselves that even they had HIV, they could support themselves and some could support their families as well. A male participant was proud that he could support himself and did not have to bother his parents and siblings. He said the following:

Now I can work. I don't bother anyone. I feel proud that I can live so long like this... Nowadays I bother no one even my parents or relatives. I look at the others who are not infected. They still rely on their parents. (6/1: p14, 8-11)
 ตอนนี้ผมทำงานได้ ไม่รบกวนใคร เราอยู่ได้นานขนาดนี้ ก็รู้สึกภูมิใจ ... ตอนนี้ผมก็ไม่ได้รบกวนใคร พ่อแม่พี่น้อง เรามองไปถึงคนอื่น ญาติพี่น้องเราที่เขายังคืออยู่ เขายังรบกวนพ่อแม่เลย (6/1: p14, 8-11)

Another participant, who was a father of two children, said:

The fact that I can help myself and be responsible for my children till now makes me proud. I could support my children till they graduated. During the infection time, my life was useful. I'm still worthy. This truth created my morale. Even though I'm infected like this, I can be responsible for my family. While someone such as some of my cousins couldn't rely on themselves though they were not like me. Sometimes I had to help them. This feeling sustained me to work for tomorrow. (17/2: p7, 25-32)
 เราสามารถประคองตัว เลี้ยงลูกมาได้ขนาดนี้ ก็เป็นสิ่งที่ผมมีความรู้สึกภูมิใจในตัวเอง เราสามารถเลี้ยงลูก ดูแลลูกได้ ส่งเสียให้ลูกเรียนจบได้ ระยะเวลาที่เป็น(ติดเชื้อHIV)มา เราไม่ได้เปล่าประโยชน์เลย ยังมีค่า จุดนี้ให้กำลังใจเรา ขนาดเราเป็นอย่างนี้ เรายังสามารถดูแลครอบครัวเราได้ขนาดนี้ ทั้งๆที่บางคนเนี่ย ญาติพี่น้องบางคนของเราเนี่ย ไม่ได้เป็นอย่างเรา ยังไม่สามารถประคองตัวเองให้รอดเหมือนอย่างเรา บางครั้งเรายังต้องช่วยเหลือพวกเขาแล้ว ความรู้สึกนี้ก็เป็นกำลังใจให้เรา มีแรงทำงานได้ (17/2: p7, 25-32)

Some participants dedicated themselves working for other infected people, community, and society. They became lecturers for many places just to make the society understand people with HIV and to let the society know that with HIV people still could live long, could have a good health if they take a good care of themselves, and could live with other people. They would give advice, pass on their experiences of facing all the problems and how to take care of themselves to newly infected people and families. They visited, suggested, and took care of AIDS patients in their house and hospitals. Moreover, they collaborated with hospitals, and the public and private organizations in helping the infected people in needs. These participants would feel self-worth and become so much happy as stated by a male participant as follows:

Nowadays I am so happy with this present job... The moral support I have got is from the patients who come to see me... I can help them and do many things for them. I feel worthwhile, and my heart is warm. When I'm happy, my courage is increased. It pushes me to further my work. (16/1: p11, 1-16)

ปัจจุบันผมมีความสุขกับงานตรงนี้นะมาก ... กำลังใจที่ได้รับและอยู่สู้ได้ เพราะผู้ป่วยที่เข้ามา ... เราได้ช่วยเค้า...ได้ทำอะไรต่ออะไรไป รู้สึกตัวเรามีคุณค่า จิตใจของเรามีความสุข พอมีความสุข มันก็มีกำลังใจเพิ่มที่จะทำงานต่อไป (16/1: p11, 1-16)

Another participant who worked for HIV-infected Thai people's network, talked about his work these days:

The duty I mainly respond is about the policy. For example, it was about the policy of AIDS problem solving. We have a lot of meeting with both government sectors and NGOs, especially, about the topic of medicine and treatment. Besides, we have organized the group activities and the HIV-infected groups' network. We have a training course that provides a brainstorming and group-work procedure so that they will learn how to think and work. We still lack experience and certain working skill; therefore, we learn by working...and then evaluate the outcome. We provide this kind of group procedure in every part of Thailand through the HIV-infected groups' network. In the level of group activity, there are some activities and training courses offered to develop their working concepts and skills. (1/2: p14, 13-23)

ส่วนใหญ่จะทำในเรื่องของนโยบาย เป็นนโยบายเกี่ยวกับการแก้ปัญหาเอชไอวี ต้องไปประชุมกับ NGO กับภาครัฐในแต่ละเรื่อง เยอะแยะมาก โดยเฉพาะหลังๆนี่จะเป็นเรื่องการรักษา เรื่องยา นอกจากเรื่องนโยบายก็จะเป็นงานกลุ่ม งานเครือข่ายผู้ติดเชื้อ ที่จะไปจัดอบรม ทำงานร่วมกับเขา ในกระบวนการที่จะชวนเขาคิด ชวนเขาทำงาน พวกเขายังขาดประสบการณ์ ยังไม่มีทักษะในการทำงานเท่าไร ก็จะได้เรียนรู้จากการทำงานไป ... สรุปกันไป ประเมินกันไป ไปจัดช่วยเขาในกระบวนการแบบนี้ ในเครือข่ายแต่ละภาค หรือในระดับกลุ่มก็จะมีกิจกรรมที่ทำกัน ที่จะอบรมกัน เสริมทักษะเขา เสริมแนวคิดเขาเรื่องการทำงาน (1/2: p14, 13-23)

Living in harmony with HIV

In this stage, the participants knew how to live healthily with HIV. They knew how to take care of themselves, both physically and mentally. They were not afraid of HIV anymore. The knowledge about HIV infection or AIDS and the management of health and illness that they had learned and developed in the former stage constituted the ways of living with HIV. Some participants saw HIV as a living part in the body. So taking care of their health meant taking care of HIV in their bodies as well. Some participants refused to take ARV drugs and tried to take care of their health instead. These participants thought that ARV drugs destroyed not only the virus but also their bodies. Some participants expressed these sentiments:

I only think that it [HIV] has been inside my body already, so it is my friend. We would hang around together. I will take care of it as a friend and do no harm to

it. I mean I won't take any drugs to kill it. When having food, I would eat more on its behalf. So I have to eat a lot. (12/1:p15, 21-26)

ผมคิดอยู่อย่างนึงว่า เขา[HIV]อยู่ในร่างกายผมแล้ว มันก็เป็นเพื่อนผม ไปก็ไปด้วยกัน เทียวก็เที่ยวด้วยกัน จันทก็จะดูแลเพื่อนเหมือนกัน และจะไม่มีการฆ่าเพื่อน ก็คือ ถ้ามียาตัวไหนฆ่าเพื่อน ผมก็ไม่กินเข้าไป เวลากินข้าวก็จะกินแทนเพื่อนด้วย ก็จะกินให้ตนเอง และกินแทนเพื่อนด้วย ก็ต้องกินเยอะๆ (12/1: p15, 21-26)

Doctors just determine that this virus must be killed by this or that method. However, I feel that now that the germ is inside my body, don't say that you would kill it. I think it is a living part in my body. If you kill it, our cells would also be killed, right? Don't think that everything would finish after its death. It might be something more. According to some symptoms our friends were suffering from, are you sure it is caused by side effects of the drugs? No, stop thinking that. We think too much. A drug has been declared to be able to kill the virus. Even though someone didn't find any virus after using the drug, he got some side effects like tumors and diabetes. These were good lessons for us. (2/1: p26, 29 – p27, 8)

หมอเขาบอกว่าเชื้อโรคมันต้องถูกฆ่าด้วยวิธีการเหล่านี้ เหล่านี้ แต่เรารู้สึกว่าเชื้อโรคมันอยู่ในตัวเรา และเราก็เป็นตัวคน อย่าบอกว่ามันต้องถูกฆ่าแบบนี้แบบนี้สิ เรารู้สึกว่ามันเป็นอะไรอย่างหนึ่งที่มีส่วนร่วมกับชีวิตเราด้วย ถ้าฆ่ามันตาย แล้วเซลล์เราจะตายไปด้วยมัย อย่าคิดว่ามันตายแล้วมันจะจบเรื่องสิ มันต้องมีอะไรมากกว่านั้นหรือเปล่า อาการบางอย่างที่เพื่อนๆเป็น เป็นผลจากยาหรือเปล่า อย่าเพิ่งบอกว่าคิดมาก เหมือนอย่างยาที่ประกาศว่าฆ่าไวรัส จนมีบางคนหาเชื้อไม่เจอ พอตอนหลังพบผลข้างเคียง มีเนื้องอก เบาหวาน หลายๆอย่างนี้เป็นบทเรียนให้เรา (2/1: p26, 29 – p27, 8)

However, some participants took the drugs and found that they worked effectively to decrease the virus level and increase their blood immune level.

The participants would always try to search for new information of the cure of AIDS, observe how their bodies change, have regular health check-ups, and keep up with the treatment. Some participants took medications against the virus, while others took drugs to prevent opportunistic infections. Some participants took vitamins or herbs as they had tried and found that these supplementary medicines could boost the immune level or reduce the side effects of the ARV drugs.

As for the mental aspect, they always observed their mental state and their emotions. They tried to relax and not to worry about something for a long time. They stopped taking people around them into too much account. They lived with the present, thinking and doing things just for the present. They were satisfied with what they were and what they had. Also, they did not try to search for something else since it might cause them to be upset as some participants stated as follows:

I was very happy now... Greedy, partiality, anger and so on...meant nothing to me. No need to be greedy. Just do today's best was enough, I thought. Now I asked for nothing more. (16/1: p16, 32 – p17, 5)

ทุกวันนี้ผมมีความสุขมาก ... โลก โมหะ โทสะ อะไรต่ออะไร...เพื่ออะไร โลกไปก็แค่นั้น เอาแค่วันนี้ให้รอดของวันนี้ได้พอแล้ว ผมคิดแค่นี้ ถ้าจะให้ได้เต้า ไปไอ้โน่นไอ้นี่ ตะเกียกตะกาย ผมคงไม่ไป (16/1: p16, 32 – p17, 5)

Till now I didn't think that my infection was my problem. Though it was inside me, I didn't see it as a problem. I felt indifferent... Now I was still alive... I felt my life was happier. Since I could come to term with the truth... I felt like there was no need to be ambitious. Before I had been infected, I dreamt a lot and it made me suffer. But now that I was infected, I could see the uncertainty of life. I had learned how to enjoy my life in the way I didn't bother the others. I felt quite good when I could help the others though it was just for a little thing. I didn't think that my life would be worse after I was infected. Now I sometimes even forgot about my infection. (4/1: p12, 27 – p13, 9)

ถึงตอนนี้แล้วเราไม่ได้มองว่าการติดเชื้อเป็นปัญหาของเรา มันอยู่ในร่างกายเรา แต่ไม่ได้มองมันคือตัวปัญหา รู้สึกเฉยๆ...เราก็ยังใช้ชีวิตอยู่อย่างนี้ได้ ... เรารู้สึกว่าเรามีความสุขกว่าตอนที่ไม่ได้ติดเชื้อ ตอนที่ติดเชื้อแล้ว และหลังจากที่เข้าใจได้ ... เราารู้สึกเราไม่ได้ดิ้นรน เราไม่ต้องดิ้นรนไขว่คว้าหาอย่างอื่น ก่อนนั้นเรามีความหวัง เราหวังจะเป็นนั้น เราหวังจะเป็นนี้ แล้วทำให้เราทุกข์ แต่ตอนนี้เราติดเชื้อ เราเห็นอะไรเยอะ เริ่มมองเห็นความไม่แน่นอนของชีวิต คือมีความสุขกับการใช้ชีวิตโดยไม่ทำให้คนอื่นเดือดร้อน หรือได้ช่วยเหลือคนเล็กๆน้อยๆ เรารู้สึกดีกับตรงนี้ ไม่ได้คิดว่าฉันติดเชื้อแล้ว ชีวิตจะต้องเปลี่ยนไปในทางลบ ตอนนี้บางครั้งลืมไปว่าตัวเองติดเชื้อ (4/1: p12, 27 – p13, 9)

Some participants tried to understand other people and look for the positive side of things. They had their own ways to relax, build up mental strength, and encourage themselves. Some of them tried to calm down by doing meditation. They believed that it would help them face any critical situation, even the illness and death.

Developing a Warm Family

One important wish or dream of several participants was to have a warm and loving family. In other words, they wanted to have a good husband or wife and good kids. Some of them had this dream before they had HIV. They thought their dream could never come true when they had HIV. For example, a male participant who had a nice family talked about his thought in those days after knowing his HIV infection:

It was impossible that those who were not infected would dearly love us and live with us. Though we knew that it could be protected, nobody liked to take a risk by living with us. Certainly I couldn't have children. I had dreamed of my own family and my children. The dream I used to look forward to would never come true. (1/1: p10, 11-15)

มันคงเป็นไปได้ ถ้าคนที่เขาไม่ได้ติดเชื้อ แล้วเขาจะรักเรา หรืออยู่ร่วมกับเรา ถึงแม้จะบอกว่ามันป้องกันได้ แต่คงไม่มีใครจะมาเลี้ยงกับเราแบบนั้นหรอก และที่แน่ๆคือ เราไม่ถูกใจได้ ชีวิตที่เลขหวังว่าจะมีครอบครัว มีลูก คงเป็นไปได้แน่ๆ (1/1: p10, 11-15)

Some participants got married with HIV-infected persons and developed their warm families. Most of them knew each other after joining the activities of the HIV-infected groups or organizations. These participants avoided having non-HIV-infected boyfriends or girlfriends as they reasoned:

I had a girlfriend who was also infected. Did I have a chance to flirt with another girl? Of course, but I didn't do that. If I did, I would tell her about my infection. Although she could accept me, I still thought I was selfish. However, could she accept who I was? Besides, I concealed it and told her later... But I thought it would be too selfish. (6/1: p15, 14-18)

ผมหาแฟนผู้ติดเชื้อด้วยกัน ซึ่งถ้าถามว่า ผมมีโอกาสกับผู้หญิงอื่นมั้ย ผมมี แต่เราไม่เอา ถ้าเราเอาเราน่าจะบอกเขาว่าเราเป็นอย่างนี้ แต่ถึงเขาจะรับได้ยังไง ก็ต้องคิดว่าเราเห็นแก่ตัวอยู่แล้ว แต่เขาจะรับได้หรือ นอกจากเราปิดบัง แล้วมาบอกทีหลัง มันก็เห็นแก่ตัวไป (6/1: p15, 14-18)

I didn't want to cause any trouble. I was fed up with having to tell others what I was. I didn't want to be insulted afterwards although he could accept me now...If one day he didn't love me anymore, I wouldn't care if he wasn't infected by me. But if he was infected, he could blame me that it was my fault. (2/3: p1, 22-26)

เราไม่อยากให้เกิดปัญหายุ่งยาก เนื่องกับการที่จะต้องบอกว่าเราเป็นอะไร ไม่อยากให้มีใครกล่าวโทษกันทีหลัง ถึงแม้ตอนนี้เค้าอาจจะยอมรับเราจริงๆ แล้วถ้าเกิดหมดรักไปวันไหนจะทำยังไงหมดรักไม่ว่า ถ้าเค้าไม่ติดเชื้อ แต่ถ้าหมดรักแล้วเดี๋ยวมาติดเชื้อ แล้วใช้คำนี้มาประณามเรา (2/3: p1, 22-26)

If the couple were both HIV-positive, they were better able to understand each other. Love, understanding, and being close to each other made them decide to get married, live together, and take care of each other. Some participants also wanted to prove that people with HIV had the right to be married and live like everybody else. A female participant who had been married for around six years recalled the social value on the marriage of HIV-infected people at that time, her thought and her decision to get married and celebrate her wedding were as follows:

At that time there was a thought that HIV-infected persons shouldn't get married. You shouldn't have your own family. It meant that you should take best care only of yourself. This thought was a thought in society in general... Even HIV-infected people agreed with it. Having own family meant increasing the burden of your life. It was as if what you were suffering from wasn't enough! ... I felt that I needed someone to live with me. It was more than "married" in simple sense, that is, living together and having sex. To me, it means sharing both happiness and sorrow. We have to help each other since we know we have got

the same trouble. At that time I decided to get married and celebrated our wedding because I didn't want the others to look down upon us like...we, both with HIV infection, could have sex every time we needed. ... It is a human instinct to need friends and love. We need a friend who could live with us... I'm also an ordinary person...I also need my own family life. (2/3: p1, 32 – p2, 29)

ตอนนั้นยังมีความเชื่อว่า ผู้ติดเชื้อไม่ควรที่จะแต่งงาน ... ไม่ควรมีชีวิตครอบครัว คือต่างคนน่าจะรับผิดชอบชีวิตตนเองให้ดีที่สุดดีกว่า อันนี้เป็นความคิดของสังคมโดยทั่วไป ... แม้กระทั่งผู้ติดเชื้อเองก็คิดอย่างนั้น จะมองว่าถ้ามีครอบครัวก็คือ การสร้างความยุ่งยากของชีวิตเพิ่มขึ้น น่าจะรับภาระตัวเองก็พอแล้ว แค่นี้ยังไม่พออีกเหรอ ... เราารู้สึกว่าเราอยากจะมีใครคนหนึ่งที่อยู่เป็นเพื่อนร่วมทุกข์ร่วมสุข มันมากกว่าชีวิตคู่ในสายตาของคนทั่วไป ที่ว่า อยู่ด้วยกัน มีเช็กส์ด้วยกัน แต่สำหรับเรา เราจะต้องร่วมทุกข์ร่วมสุขนะ มีอะไรเราจะต้องช่วยกัน เรารู้ว่าเรามีปัญหาเดียวกัน ตอนนั้นตัดสินใจแต่งงานและจัดพิธีแต่งงานด้วย เพราะเราไม่อยากให้ใครมาดูถูกว่า ผู้ติดเชื้ออยากจะมีลูกกัน อยากจะมีอะไรกันเมื่อไหร่ก็ได้ ... ส่วนหนึ่งมันเป็นเรื่องของธรรมชาติของมนุษย์ที่ต้องการเพื่อน ต้องการความรัก และเพื่อนที่จะอยู่ด้วยกัน ... ซึ่งเราก็คือคนปกติ ... เราก็คือต้องการชีวิตครอบครัว (2/3: p1, 32 – p2, 29)

She talked about her married life as follows:

To us, living together means sharing life together because we are in the same boat. We have encountered the same trouble, so we understand each other more. We have to rely on each other. For example, when we see doctors, both of us pay attention to our trivial matters. We understand each other more because we don't know how long we would be together... That's why we can reconcile very fast after an argument. It's like the normal couples. Sometimes we get mad, but though we feel angry with each other, we make up shortly after that. (2/3: p2, 29 – p3, 8)

สำหรับเราแล้ว เราอยู่ด้วยกัน เราให้กันมากกว่า เพราะเราอยู่ในสถานะที่เหมือนกัน ผ่านปัญหาที่เหมือนกัน ความอดทนที่มีต่อกันเรามีมากกว่า เวลาพิ่งพาอาศัยกันก็มีเยอะกว่า อย่างพาไปหาหมอ เรื่องเล็กๆน้อยๆเราจะใส่ใจกันมากกว่าคู่ปกติ เรามีความเข้าใจกันมากกว่า เพราะเราไม่รู้ว่าเราจะมีช่วงเวลาที่อยู่ด้วยกันนานแค่ไหน เพราะฉะนั้นอะไรที่ขัดหูขัดตา กัน หรือคิดใจกัน มันรู้สึกว่ามันก็กลับมาจนหาได้ง่าย มันก็มีเหมือนคู่ปกติมันแหละ จอนกัน โกรธกัน แต่มันก็จะกลับมาหากันได้เร็วกว่า (2/3: p2, 29 – p3, 8)

Besides, they wished to have children like ordinary couple. Some of them were pregnant, but they couldn't sustain the pregnancy because of the health problem, and they finally had to undergo an abortion. Some couple wanted to have babies, but when they thought of the future of the babies and realized how insecure their lives were, they decided not to go through with it. Some couples adopted other infected people's children whose parents had died. Other couples decided to have their own children whether their children were infected or not. Having a family and taking care of them was one of the happiest things in their lives as one female participant remarked:

Now I am happy. I feel happy with my life and my good family. My relatives understand me. I am happy that I can spend my life watching over my children and husband. It is the family I had dreamt of. I wish I would have a good husband and lovely children. However, while I wasn't infected, I couldn't make my dream come true. After being infected, I find that my husband is very best. My children are so lovely as well. So, I am happy to watch over them. (4/1: p20, 26-32)

ตอนนี้รู้สึกตัวเองมีความสุขดี รู้สึกมีความสุขกับการใช้ชีวิต มีครอบครัวที่ดี ญาติพี่น้องเข้าใจ มีความสุขกับการใช้ชีวิตที่ได้ดูแลครอบครัว ลูก สามี มันเป็นครอบครัวที่เราฝันถึง อยากจะมีลูก อยากจะมีสามีที่ดี แต่ไม่เคยเจอตอนที่ยังไม่ติดเชื้อ พอติดเชื้อแล้ว แฟนเขาเป็นคนที่ดี เป็นผู้ชายที่ดี มาก มีลูกน่ารัก ก็เลยมีความสุขกับการได้ดูแลเขา (4/1: p20, 26-32)

Preparing for terminal illness and death

Seeing the uncertainty of life and realizing being able to die anytime made the participants live carefully. They made themselves ready to face the terminal illness that would occur in the future and also for the death that everyone has to go through sooner or later. They would do what they wanted or intended to right away and did it with all their might because they did not know if tomorrow would come and how long they would live. Therefore, every minute counted for them, as can see in the following quotation:

I think the advantage of being infected is to live without carelessness. I mean what I still don't do, I would do it...After I was infected, I immediately did everything I needed... I wouldn't postpone it because I didn't know whether tomorrow would come... The future is not important. Today is the most important. So, just begin to do what you want to do today. (12/1: p21, 3-16)

ผมมองว่าข้อดีของการติดเชื้อก็คือ การใช้ชีวิตอย่างไม่ประมาท ก็อบางสิ่งบางอย่างที่เรายังไม่ได้ทำ เราก็จะรีบทำ ... พอผมติดเชื้อ สิ่งไหนที่ผมอยากทำ ก็จะทำเลย จะไม่มีผลัดวัน เพราะผมไม่รู้ว่าวันพรุ่งนี้จะมีหรือเปล่า ... อนาคตคือสิ่งที่ไม่สำคัญ แต่สำคัญที่สุดคือวันนี้ วันนี้เราต้องทำอะไร เราทำวันนี้เลย (12/1: p21, 3-16)

They would plan and make the arrangements for their terminal illness and death though they were still healthy. Some participants contacted or planned to find places that provided help and care to AIDS patients to be their shelters when they became pretty sick. For example, a male participant did not want to bother his parents and planned to find a shelter to live when he got severe illness. He said the following:

I just think that I don't want to be a burden of my parents when my health becomes worse... When I am in the severe stage, I will find somewhere that offers healthcare to the last-stage patients. (6/2: p3, 7-23)

ผมคิดอยู่ว่า ถ้าเราป่วย เราทรุด...เราก็คงไม่อยากจะเป็นภาระพ่อกับแม่ที่ต้องดูแล ... ถ้าเราป่วยหนักจริงๆ ผมคงจะหาสถานที่รองรับผู้ติดเชื้อในระยะสุดท้าย (6/2: p3, 7-21)

Some participants tried to practice meditation to help them endure the sufferings from the terminal illness and die peacefully. Some of them believed in the reincarnation, so to practice meditation would also help them have a good life after death. They believed that all people had a soul that existed in the body. When people died, the soul could slide into something to be reborn. If ones could control the mind in a calm state through meditation when death finally arrived, the soul could get to a pleasant place or be reborn in a next good life. A male participant shared his belief:

I rather believe in the circle of life. So, I think the most terrifying thing is not the death. The life behind the death looks more fearful. (19/1: p13, 18-20)

ผมค่อนข้างจะเชื่อเรื่องการเวียนว่ายตายเกิด และสิ่งที่น่ากลัวที่สุด ไม่ใช่ชีวิตที่อยู่ตรงนี้ ชีวิตหลังความตายน่ากลัวกว่า (19/1: p13, 18-20)

He learned about Buddhist teaching and meditation firstly from his mother and then from some monks. He had practiced meditation quite regularly for over ten years. He thought it was the needed means for a good life after death, and he believed he could do it well. He stated:

I have *plong*. I mean I am afraid of nothing. About the cause of death, I am scared of accident more than sickness. To die by a disease, I think I would have enough consciousness. I would do meditation till the last breath. However, if I suddenly die by accident, I would die with doubt. (19/1: p17, 1-3)

ผมปลงแล้ว ก็คือไม่กลัวอะไร ถ้าจะตาย กลัวอุบัติเหตุมากกว่า ไม่กลัวการเจ็บป่วยแล้วตาย การเจ็บป่วยแล้วตาย ผมคิดว่าผมมีสติพอ ตอนนั้นผมคงเข้าสมาธิแล้วผมคงไปได้ดี แต่ถ้านั่งๆอยู่ดูมไปอย่างนี้เราไม่รู้ว่ามีอันคืออะไร (19/1: p17, 1-3)

Some participants kept their legal documents ready all the time. Others planned for their properties and people under their patronage like children and parents. They also prepared for their funeral ceremony and its expenses. A widowed participant, who had a son, aged nine years old and an old mother under her support, had planned about her son's and her mother's living if she would finally go away. She talked about her plan as follow:

I have planned that I'd like my child to be a student of the Islamic boarding school for orphans. However, I haven't called them yet... It is a boarding school for orphans. So, at least my child will be close to religion. This school will support the students till the highest level they can study. First, I decided to send my child there this year but I felt so sorry for him. I am now waiting for the next year because I am still healthy... About my Mom, I told her to stay in the retirement home if I got worse...I asked her whether she could do it and she said she could. (3/1: p8, 13 – p9, 3)

หนูเตรียมไว้ว่า อยากให้ลูกเรียนโรงเรียนประจำของอิสลามที่เลียงเต็กกำพร้าว แต่ยังไม่ได้ติดต่อ... เป็นโรงเรียนกินนอน รับเฉพาะเด็กกำพร้าว อย่างน้อยลูกจะได้อยู่ในศาสนา เค้าจะส่งเด็กเรียนเท่าที่เด็กจะเรียนได้ ที่แรกจะฝากปีนี้ แต่ส่งสารลูก รอให้ปีหน้าก่อน เพราะหนูยังแข็งแรง ... ส่วนแม่ ก็บอกแม่ว่า ถ้าวันไหนหนูไม่ไหวให้ไปบ้านพักคนชรา ... ก็ถามว่าแม่อยู่ได้มั้ยเค้าก็บอกอยู่ได้ (3/1: p8, 13 – p9, 3)

Another female participant and her spouse, who was also HIV-infected had prepared something for their daughters, who were one and four years old. She said the following:

I have made a photo album and some short descriptions of our family in order that my children will understand the relationships in the family. They will know more about their parents. I also made a home video about the family's events and a diary I want my children to read some messages I have written to them... Ordinary people usually neglect this thing, while a lot of HIV-infected people always think of it and really pay attention to it... We would feel more released if we have prepared ourselves for death. When we die from whatever reason, we are sure that we have left some mementos for those who are left behind. (2/4: p1, 5-15)

หนูได้เตรียมรูปภาพพร้อมเรื่องเล่าที่แสดงถึงความเป็นไประหว่างครอบครัวของเรา โดยมีจุดประสงค์เพื่อให้ลูกได้เห็นถึงความสัมพันธ์ของครอบครัว ให้เขาได้รู้จักพ่อแม่ แล้วถ่ายวิดีโอเก็บไว้ ซึ่งแล้วแต่เราอยากจะถ่ายช่วงไหน เรามีสมุดบันทึกที่เราจะเลือกเก็บข้อความถึงลูก ... คนทั่วไปมักจะไม่ได้ใจเรื่องนี้ แต่ผู้ติดเชื้อหลายคนมักจะคิดถึงเรื่องนี้และใส่ใจกับเรื่องนี้มากกว่า เพราะการเตรียมตัวสำหรับความตายอยู่เสมอ ทำให้เราสบายใจมากขึ้น ไม่ว่าเราจะตายด้วยอะไรก็ตาม เราได้มีสิ่งที่เป็นของที่ระลึกไว้สำหรับคนข้างหลังแล้ว (2/4: p1, 5-15)

Some participants had prepared for their funeral ceremony and its expenses:

Some day I would die. Now I have prepared for everything. I have already discussed with my wife and planned about the future. We should have some money for our funeral, so we would bother no one. All my savings from the social security or other sources would be given to my parents... We just *tham jai* with it. Just die...when death arrives. (6/1: p14, 13-19)

สักวันถึงวันนั้นที่เราต้องไป ตอนนี้เราก็เตรียมไว้ทุกอย่าง ผูกอยู่กับแฟน เตรียมหมดเลย เราต้องเตรียมเงินนะ ก่อนนี้ไว้เป็นค่าทำศพ ไม่ต้องรบกวนคนอื่น เงินสะสมที่เราได้มา ไม่ว่าจะเป็นเงินจากประกันสังคม หรืออะไร เราจะยกให้พ่อกับแม่หมด ... ก็ทำใจ เตรียมตัวเตรียมใจ ถ้ามันจะตาย มันก็ต้องตาย (6/1: p14, 13-19)

I just think I'm near-death now. I feel like I have spent my lifetime so long and now I'm ready for everything. I'm ready to die. I have prepared for my funeral by contacting the temple and preparing my funeral expenses. Now I'm free and ready to die. (12/2: p10, 6-9)

ผมมองว่าผมใกล้จะไปแล้ว เรามีความรู้สึกว่าเราอยู่นานแล้ว ผมคิดว่า ตอนนี้ผมก็พร้อมทุกอย่างแล้ว ถ้าไปก็พร้อมหมดแล้ว วัดผมก็ติดต่อไว้แล้ว เงินค่าทำศพก็เตรียมไว้เรียบร้อยแล้ว ภาวะตอนนี้ก็คือเฉยๆแล้ว ก็สามารถไปได้ทุกเมื่อ (12/2: p10, 6-9)

These preparations made the participants ready to go away anytime and feel released, as stated by a male participant as follows:

I feel released because I know that I'm ready. I am not worried about that matter any more. (12/2: p10, 11-13)

ผมรู้สึกสบายใจ ที่เราสบายใจก็เพราะว่าเรารู้ว่าเราได้เตรียมพร้อมแล้ว เราไม่ต้องมานั่งกังวลในจุดนั้นแล้ว (12/2: p10, 11-13)

Intervening conditions

The conditions that influenced the participants' strategies in this stage were some personal factors and their communities' acceptance of HIV-infected people. These conditions made some differences in their action and interaction strategies to live normally with HIV infection.

Personal factors

The personal factors included occupation, developmental state, responsibility in their families, and personal belief. The participants who had their own business or worked as government officials or employees usually lived normally with their HIV status concealed from people in their community and from their colleagues. In contrast, the participants who worked for HIV-infected groups or organizations or the NGOs working on AIDS mostly disclosed their HIV status to the community or the public. The young-adult participants usually desired to have their own family life or needed someone to live with, so they made it come true. On the other hand, those in their middle age already had their own family and took responsibility in supporting their children. The participants' responsibility in their families and personal beliefs influenced what they did before their death came. Some participants prepared for their children's and parents' living condition, some prepared mementoes for their children, and others prepared themselves to have a peaceful death and a good next life.

Community acceptance

The community's acceptance of HIV-infected people was another condition that influenced the participants' actions in living and working in the community. With the community's acceptance, the participants could live and work in the community with complete disclosure. They could talk about their HIV infection openly to everyone in the community. Moreover, they could help other HIV-infected

persons in their community by sharing their experiences and giving advice. They could also educate people about HIV/AIDS.

Consequences

Living with the family warmly and living normally in the community made the participants happy. Working and doing something useful for the family, community, and society made them proud of themselves, increased self-worth, and resulted in their satisfaction with their lives. Preparing themselves for terminal illness and death and preparing something to be left for others made them feel released. It meant they were ready and confident to face the terminal illness and death.

In conclusion, living normally was a state that the participants perceived themselves and went on with life as ordinary persons in the society. The participants who moved into the stage of living normally, perceived themselves and their lives as normal people. They thought that they had potential and a life like ordinary people. Their perception about HIV infection or AIDS had changed in a positive way. HIV infection or AIDS was viewed as just a chronic disease that was treatable though not curable. It did not cause a sooner death. They could live for a long time by taking a good care of themselves. It was not a disgusting disease either. Some participants thought that HIV was a company living together or a part of their life, and others viewed it as an opportunity of life. The participants had competence in managing health and illness and felt confident to live with HIV.

The participants' strategies in this stage included living together with the family and community, working, living in harmony with HIV, developing a warm family, and preparing for terminal illness and death. The participants were satisfied with their lives. They lived happily with their family. They felt proud of themselves and had more sense of self-worth. Moreover, they were confident and ready to face the future illness and death.

CHAPTER V

DISCUSSION

The substantive theory of this study was the process of fighting to live normally with HIV infection. It was defined as the process that the long-term HIV-infected participants continuously exerted both cognitive and behavioral efforts to struggle against or overcome their suffering as well as many problems or difficulties created by HIV infection in order to achieve a state of living normally. It was composed of four consecutive stages: flight, pulling oneself together to fight, fighting for existence, and living normally. The causal, contextual, and intervening conditions; the action and interaction strategies; and the consequences, which constitute these stages, were interrelated and dynamic in nature. The causal, contextual, and intervening conditions in each stage influenced these participants' action and interaction strategies, which then created the consequences that usually in turn became new causal conditions in the next stage.

For clarification, the discussion of the findings will be elaborated in each stage of the process of fighting to live normally with HIV infection. The existing concepts, theories, and previous studies will be compared with the findings. The purpose of this comparison is to determine the similarities and differences between the findings and those previous relevant concepts, theories, and studies, and also to identify the specific contributions of the current study.

Stage 1: Flight

The stage of flight began after long-term HIV-infected participants learned about their HIV infection. All of them perceived HIV infection as a terrible disease that was incurable, caused a sooner death, and was disgusting. Therefore, they were overwhelmed with distressed feelings including sadness, hopelessness, fear, and anxiety. The participants' mental condition at that time was similar to the emotional crisis phase, which was described as an initial phase in which HIV-infected people

felt distressed and still could not adjust their emotions and thoughts (Sangchat, 1998: 86-87). Their perception of HIV infection or AIDS was congruent with the findings of a qualitative study, which was conducted about ten years ago and reported that HIV-infected Thai people perceived AIDS as incurable and death only (Chaiphibalsarisdi, et al., 1991: 13). This previous research was done in the same social context and nearly to the same time as when the participants of the current study firstly knew their HIV-status. It was also similar to another qualitative study, which reported that most Thai mothers (90%) who had lived with HIV for less than two years perceived HIV infection or AIDS as a life-threatening disease, a contagious disease, and a shameful disease (Thampanichawat, 1999: 77-86).

Such perception of the disease was influenced by negative social images of HIV infection and AIDS and negative social reactions to HIV-infected people, which were the social context at that time. HIV infection and AIDS were viewed through the broadcast media around the country as an incurable disease, a disease of death, and highly contagious disease. The image of persons with HIV or AIDS was horrible, deviant, or bad, and Thai people generally reacted to them with great fear and disgust. The previous studies which described the HIV/AIDS media and social and cultural dimension of HIV/AIDS in Thailand (Charusab, 1997: 343-354; Lyttleton, 1996: 363; Songwathana & Manderson, 1998: s155) validated the images and reactions described by the participants in the current study.

Another contextual condition that reflected the great fear of the society toward HIV-infected people and the lack of understanding of the disease among healthcare providers was the use of the “Monitoring and Controlling Patients Who Caught Serious Infectious Disease” Act 1985 in Thailand during the years 1985 to 1989. Under this Act, the HIV-infected people had to be monitored in the community by the public health officials. This caused the disclosure of their HIV status to family and community and resulted in family and community rejection.

When perceiving HIV infection or AIDS as a terrible disease and being overwhelmed with distressed feelings within these social contexts, the participants performed the action and interaction strategies including keeping secret, avoiding social contact, leaving home and community, and having unwillingness to live. These strategies were conceptualized as flight which made them avoid facing the problems

or the situations related to their HIV infection. These avoiding strategies were equivalent to the emotion-focused coping strategies which are directed toward decreasing emotional distress and are the more common form of coping used when events are not changeable (Lazarus, & Folkman, 1984: 150-153). Avoiding strategies might be appropriate and needed for HIV-infected people in these conditions to protect themselves from the society's adverse reactions and to decrease their emotional distress.

This suggestion supports the findings of a number of previous studies which indicated that avoiding or emotional-focused coping was an appropriate way for HIV-infected people to handle the inescapable life-threatening infection in the asymptomatic period (mostly in the first few years of the disease). This is because it was found that avoiding or emotional-focused coping in asymptomatic HIV-infected people was associated with less progression of HIV disease (Mulder, et al., 1999: 110-111) and positively related to quality of life (Rose & Clark-Alexander, 1996: 31-32). The current study's findings are also congruent with a number of research results, which found that avoiding coping was related to greater distress, mood disturbance, anxiety, and depression (Fawzy, Namir & Wolcott, 1989: 35; Fleishman & Fogel, 1994: 156; Leserman, Perkins & Evans, 1992: 1514; Namir, et al., 1987, cited in MacIntyre & Holzemer, 1997: 34; Nannis, Patterson & Semple, 1997: 13; Wolf, et al., 1991: 171).

However, these participants' strategies and the time they consumed in the flight stage somewhat varied according to the participants' intervening conditions. These conditions were the healthcare system that they experienced and their family system. The findings indicated the characteristics of the healthcare system that helped decrease HIV-infected participants' fear, anxiety, and the suicidal incidence. They should beware as follows: assuring confidentiality, informing the HIV-blood test result personally and directed to the infected person, providing the information about the disease and counseling, and providing healthcare to these people without any manner of discrimination. As for the family system, the closed and warm relationship and the responsibility in supporting one another in the family would help the participants pass the stage of flight rapidly and prevent them from entertaining a suicidal idea.

Some strategies and intervening conditions in this stage were supported by other previous qualitative studies which noted that some HIV-infected Thai people isolated themselves, did not talk to anyone, and might harm themselves in response to the diagnosis of HIV infection. The psychological adjustment of them in the first two weeks of the diagnosis depended on their conditions of living with others and the responsibilities to the family (Chaiphibalsarisdi, et al., 1991: 18-31; Pradabmook, 1994: 40-45; Prohmpakdee, 1994: 129).

At the end of this stage, the participants' perception of the disease was not changed. They suffered from their distressed feelings and loneliness. Some participants, especially those who left their home, had to encounter the difficulties in living with little or no support. These sufferings seemed to be the forces that pushed these participants to do something to relieve themselves from misery and enter the stage of pulling oneself together to fight.

Stage 2: Pulling Oneself Together to Fight

The stage of pulling oneself together to fight was a transitional stage in which long-term HIV-infected participants changed themselves from flight to fighting, or from avoiding the situation related to HIV infection to encountering it. The conditions of the participants at the time when they moved into this stage were sufferings and the realization of sooner death.

The condition of sufferings led the participants to seek help from others and make efforts to overcome them. They sought help from family, healthcare providers, HIV-infected friends, and respected spiritual matters. They overcame the distressed feelings by alleviating the feelings and '*tham jai*.' *Tham jai* was the process of mental work to adjust or to control their thoughts and their feelings. By this process, the participants tried not to think about their situation, thought positively, and accepted their HIV infection and whatever that would happen to them in the future, even death. They also *plong/plong tok* by contemplating about death and realizing the reality of the uncertainty of life, and then thus made a decision to let it go.

The realization of sooner death was another condition that brought the participants to enter into the process of *tham jai*, especially in the mode of accepting

and *plong/plong tok*, and also into the process of finding the meaning in living. The latter was the process in which they sought after what was significant in their lives and made a decision about how to live or what to be done in the rest of their lives. It was composed of three sequential actions: considering about one's situation, realizing the worth of self and life, and creating a purpose of life. *Tham jai* and finding the meaning in living were two strategies that facilitated each other.

The action-interaction strategies of these participants in the stage of pulling oneself together to fight were similar to those identified by previous studies as actions or strategies to keep HIV-infected people healthy and live longer (Allan, 1990: 56-60; Barroso, 1995: 44-53; Barroso, 1999: 242-248; Gloersen, et al., 1993: 45-52). These studies investigated the perception of HIV-infected people who were asymptomatic and long-term survivors or who achieved a general sense of well being.

It was found that accepting, being positive, and experiencing support were the processes of developing a sense of well being in HIV-infected people (Gloersen, et al., 1993: 45-52).) Also, various studies found that long-term non-progressors were committed to live positively with HIV. Having a sense of purpose in life or setting and striving for goals were identified as psychosocial strategies related to chances of longer survival (Barroso, 1995, cited in Barroso, 1999: 243; Crossly, 1997: 1863-1873; Laschinger & Fothergill-Bourbonnais, 1999: 63-64). In addition, creating a meaningful life pattern was described as a way to transcend the emotional and physical suffering of people with AIDS (Mellors, et al., 2001: 235).

Accepting and being positive are the same as the two modes of *tham jai*: accepting and thinking positively, which the participants performed to relieve their distressed feelings. Moreover, experiencing support is similar to the strategy of seeking help, in which these participants received support from others. Finally, "having a sense of purpose in life," "setting and striving for goals," or "creating a meaningful life pattern" is comparable to "finding the meaning in living" which was identified as another strategy of the participants in this study. The consequences of these strategies when used by the participants were feeling relief; developing the will to live; having hope, morale, and a purpose in living; as well as realizing self-worth and the worth of life. These consequences increased their general sense of well being.

In the stage of pulling oneself together to fight, some participants in the study sought help from respected spiritual matters for relief of the suffering and reception of spiritual support. These matters were related to their religious belief, which was mostly Buddhism. Also, some participants mentioned that the Buddhist teaching and rituals such as praying, doing meditation, and considering ‘The Three General Characteristics of Existence’ (*Trilaksana*) were important things for them to overcome the distressed feeling and enabling them to continue living for over ten years. Consistently to this study, Tansriratanawong (1998) reported that HIV-infected Thai people usually used Buddhist teachings as way of coping with their illness such as practicing rituals, meditating, praying, and exchanging s with spiritual counselors or monks. In Western cultures, the long-term non-progressors also reported that the belief in a higher power and surrender to a higher power was a way of adapting and a source of strength and help (Barroso, 1999: 242-248).

Besides, social supports, healthcare providers, and personal attributes were the intervening conditions that influenced the action and interaction strategies of long-term HIV-infected participants in the stage of pulling oneself together to fight. In this stage, they sought help and support from someone whom they trusted. These people were usually the family members and HIV-infected friends who had a similar situation and could deeply understand them. Social supports that the HIV-infected participants received in this period were mostly emotional support and informational support. The roles of the supports were to relieve the distressed feelings of fear and anxiety, to encourage, and to make them realize their self-worth and the worth of life. The acceptance of families and encouragement from families and HIV-infected friends seemed to be the most crucial factor in this period.

Moreover, long-term HIV-infected participants in this study indicated that reciprocal support for each other made them feel their self-worth and facilitated the processes of *tham jai* and finding the meaning in living. This finding was consistent with a naturalistic study which reported that receiving support from others and giving support to others were seen by long-term non-progressors with HIV-infection as important factors to maintain their good health and ensure longer survival (Barosso, 1999: 246-247; Ironson, et. al., cited in Barosso, 1999: 243).

Healthcare providers have important roles in providing knowledge, information about HIV/AIDS and the existing social resources for HIV-infected people including the HIV-infected groups, as well as give counseling to the long-term HIV-infected participants. Another significant role, which could greatly help these participants, is an initiation of the HIV-infected groups in the health centers, to support and guide the HIV-infected participants who have recently known the diagnosis and join the groups.

In this study, personal attributes were another intervening condition influencing the participants' action and interaction strategies in this stage. The developmental stage, responsibility in the family, beliefs and experiences especially in religion (Buddhism) of these participants influenced the meaning they gave to their lives and the process of *tham jai* to overcome their distressed feelings. The content of Buddhist teaching that they most frequently mentioned was "The Three General Characteristics of Existence: *Anicca* (impermanence), *Dukkha* (sorrowfulness or suffering), and *Anatta* (non-self)". It explains that all forms of existence are impermanent and are subjected to decay. Therefore, existence means sorrowfulness or suffering, and none can be a self, an ego, or a soul (David-Neel, 1977: 25; Schumann, 1974: 42-47). It seemed that at the time of suffering, the participants could easily adopt and understand this Buddhist teaching. It thus facilitated their engagement in *tham jai* and finding the meaning in living. They realized the reality of life that everyone has to pass away. They could accept their conditions and make a decision to let it be. Then, they realized their self-worth and the worth of life at the present, and found out what should be done as best as they could for the rest of their lives.

With the strategies of seeking help and overcoming the distressed feelings, the participants had received emotional and informational supports. They felt less fearful and less anxious. They had hope, morale, and the will to live. Moreover, the positive changes in the perception of HIV/AIDS were gradually developed. Some participants learned that HIV infection or AIDS was not like an immediate death sentence as they had thought it was before. They could live for years if they took care of themselves and avoided the risk behaviors. Moreover, HIV was not easy to transmit to others. In addition, they realized self-worth and the worth of life and had a purpose in living through the process of finding the meaning in living. These consequences constituted

a ready state for the participants to face with their situations and enter into the next stage, the stage of fighting for existence.

Stage 3: Fighting for Existence

Fighting for existence was a stage in which long-term HIV-infected participants worked very hard to overcome many events or difficulties to continue their family's and their own lives, as well as to attain their purposes in living. The participants had to face various problems and difficulties to continue their lives under the social context of discrimination and prejudice. However, during those time the HIV-infected groups and social organizations working on HIV/AIDS in Thai society were gradually developed and provided support to these participants. The problems they encountered included enduring financial problems, losing job, getting sick, and dealing with child's and spouse's sickness and death. They had to expend all of their efforts to survive in these difficult situations.

The consequences that happened in the previous stage were the important conditions for entry into this stage. These conditions were the perception of the possibility of years left to live, realizing self-worth and the worth of life, having willingness to live, having morale and having purposes in living. With these conditions, they were strengthened enough to face the difficult situations. The action and interaction strategies the participants performed in this stage included seeking fundamental factors for living, learning about HIV/AIDS, managing health and illness, keeping up morale, as well as concealing and disclosing their HIV-infection.

Seeking fundamental factors for living was the strategy which several long-term HIV-infected participants had to firstly perform. The participants were those, who still not met their basic physical needs, such as food and living place. Some of them had to leave their home because their HIV-status were disclosed, some could not support themselves and had no place to live, and others were young and had no jobs. However, some had to perform it afterwards when they had problems that made them unable to work or support themselves. These participants had to make strenuous efforts in mobilizing the available resources both personally and socially, finding jobs and working hard to gain these fundamental factors. Some made attempts to find jobs

under social discrimination and worked so hard for their family's living because they perceived that they had only a limited time left. An attempt to seek fundamental factors for living could distract their attention from HIV infection. Moreover, they had more sense of self-worth and felt proud of themselves since they could support themselves and their family.

As for the strategies of learning about HIV/AIDS and managing health and illness, the long-term HIV-infected participants learned about the nature and the management of the disease, as well as the factors affecting their health and disease progression. They developed the skill in managing their health and illness. They performed actions to maintain their physical and mental wellness and managed the illness when they had it by using both modern and complementary therapies. These strategies were equivalent to the self-care activities, which have been reported by some studies as ways in maintaining the physical and mental health mentioned by long-term non-progressors, long-term survivors, and asymptomatic HIV-infected people (Allan, 1990: 56-60; Barroso, 1999: 246-247; LaPerriere, et al., 1997: s56-s61).

The strategy of keeping morale up was mentioned by most of the long-term HIV-infected participants in this study as the most important strategy to maintain their health. Morale (*Kam lang jai*) meant a state of mental well being in which the participants have a strengthened mind and felt confidence in facing any situation with a sense of purpose in living. Keeping morale up was the process that they tried to maintain this mental state of well being. With morale, the participants were able to use both cognitive and behavioral efforts to solve the problems they encountered.

The HIV-infected participants' morale was dynamic in nature. Their morale tended to decrease when they encountered difficult situations. They had learned that if their morale was decreased, their health would deteriorate. Therefore, they had to keep their morale up as much as possible. Keeping morale up then seemed to be a needed strategy accompanying other strategies in maintaining their health and continuing their lives.

The HIV-infected participants developed their own strategies in keeping morale up such as empowering themselves, thinking of someone or something in their concerns, reminding themselves about their purposes in living, learning from others,

and setting a possible goal. One sub-strategy “empowering self” was supported by the study of Crossley (1997: 1863-1873), which reported that it was an action of long-term non-progressors in living with HIV. The participants in the current study empowered themselves by frequently praying and reminding themselves that they had to be strong, they had to fight and to be alive, and they could do it.

The last strategy in the stage of fighting for existence is “concealing and disclosing the HIV-infection.” To conceal or to disclose the HIV-status was depended on individual conditions such as their jobs, family, and social status. Some of these conditions were similar to those identified in the studies of Wattanapailin (1996) and Thampanichawat (1999: 196-197). The participants who worked in government offices, large companies, or their own business would conceal their HIV-status since they were afraid that the disclosure of HIV-status might affect their career. The close relationship was another important condition for disclosure to family members. However, for the participants who were responsible for the family usually did not disclose their HIV-status because they were concerned that their parents and children would be sad and worried about their illness. On the other hand, some participants decided to inform their parents because they wanted to prepare their parents before they developed full-blown AIDS and died.

As time went by, the long-term HIV-infected participants had a tendency to disclose their HIV status to more people. They intended to disclose their condition to some people or some groups of people. Some intended to disclose their HIV-status to community or the public. These participants decided to disclose their HIV-status when they were ready to face the results of telling the truth. In the case of disclosure to the public, not only they themselves but also their family must be ready to face the social reactions after the disclosure. The participants who disclosed their HIV-status to their community or the public mostly worked in non-governmental organizations that worked for HIV-infected or AIDS persons.

Furthermore, some conditions influenced the long-term HIV-infected participants’ strategies in this stage. Firstly, the different problems that the participants encountered, which resulted from the differences in their family status and socio-economic background. Secondly, social support would enable these participants to pass through their difficult events. The supports they needed when they

encountered the difficulties and they could not support themselves were instrumental supports such as money, materials, and living place. And in the time that they had a serious illness, they needed healthcare and moral support as well.

It is worth noting that the sources of supports were more various than those in the former stage. These participants sought help and support from many sources including family, HIV-infected and non-infected friends, as well as governmental and non-governmental organizations. The participants who had limited resources such as having a low economic status, low education and vocational skill needed more support than those who had more resources. The role of social support in this stage was to help them became able to pass through the problems and keep going on living their lives at the time they needed.

Social supports have been found to influence the coping process of HIV-infected Thai people in a number of studies. For instance, Wattanapailin (1996: 197-198) noted that social support had influences on the coping process through their coping strategies. Moreover, Tongchom (1990: 146-152) reported that social support facilitated the behavioral adjustment of HIV-infected intravenous drug users. Also, correlational studies revealed that social support was related to psychosocial adjustment, coping behavior, and behavioral adaptation of people living with HIV / AIDS (Kabinlapat, 1998; Kusuma Na Ayuthya & Somnarin, 1997: 4; Phavady, 1996: 11; Sittichamlong, 1999). In addition, family support program was developed and its positive effect on adaptation to AIDS of HIV seropositive persons was found (Jaikaew, 1997: 121-125).

The final condition was personal resources and attributes. The participants who had limited personal resources had to seek supports from the others and social resources. Some personal attributes such as persistence and fighting spirit seemed to facilitate their strategies in seeking fundamental factors for living by mobilizing resources, finding jobs and working hard, fighting with serious illness, and keeping up morale. The participants did not easily feel discouraged or hopeless and could rapidly regain their morale while confronting with the adversity. Some of them persistently sought help and supports until they gained some.

The attributes of persistence and fighting spirit of these participants were somewhat similar to the control component of hardiness personality proposed by

Kobasa (1979: 1-11) and the manageability component of the sense of coherence proposed by Antonovsky (1987: 16-19). The control component of hardy persons is a tendency to believe and act in a way that influences their life events rather than feeling helpless when they confront with adversity (Kobasa, 1979:3). Moreover, manageability component of the sense of coherence refers to the extent to which one perceives that resources are available to one to meet the demands posed by stimuli or hardships that bombard one (Antonovsky, 1987: 19). In the present study, the long-term HIV-infected participants who were poor and had limited personal resources sought help and support from the available resources in the society when they confronted with adversities. These participants did not feel helpless and they believed that they could do something to influence their life events. Consequently, they received some help or supports, and they could keep their lives going and also maintain their health status for a long time in spite of their HIV infection.

The concept of hardiness (Kobasa, 1979: 1-11) and Antonovsky's Salutogenic Model (Antonovsky, 1979: 183-186) supported the finding of the present study. Kobasa (1979: 3) stated that "among persons under stress, those who have a greater sense of control over what occurs in their lives will remain healthier than those who feel powerless in the face of external forces." Antonovsky's Salutogenic Model (Antonovsky, 1979: 193-195) proposed that the sense of coherence will enable persons to mobilize their generalized resistance resources that promote the effective coping with the stressors and tension. Overcoming the stressors and resolving tension will maintain their health status (Antonovsky, 1979: 183-186, 193-195). In this study, the long-term HIV-infected people's action and interaction strategies could overcome the difficulties that were comparable to the stressors. They could live with HIV infection longer than average. They lived normally like they were HIV negative, and they felt happy, assured of self-worth and satisfaction with their lives. It indicated that these participants had growth, and development in living through their various and severe difficulties in life situation and could achieve well being which was some indicators of health.

Along the stage of fighting for existence, long-term HIV-infected people could meet their basic physical needs and had more sense of self-worth. Their perception about HIV/AIDS had changed considerably from a very negative to a positive view

through their learning and managing health and illness. They also developed competence in managing health and illness and the confidence in living with HIV. These consequences were the conditions that moved the participants into the next stage, the stage of living normally.

Stage 4: Living Normally

Living normally was a state in which long-term HIV-infected participants perceived themselves and went on with life as ordinary persons in the society. The conditions that led them to enter this stage were the changing perception of HIV/AIDS from a negative to a positive one, perception of self and one's life as normal people, competence in management health and illness, confidence in living with HIV, and realization of the uncertainty of life. These conditions led them to perform strategies to live normally with HIV infection. The social context had then changed to be a more supportive environment to HIV-infected people. There were many accessible HIV-infected groups and organizations well developed to be a network around the country. Moreover, the community had more understanding of HIV-infected people. Their personal factors and the community acceptance to HIV-infected people were the intervening conditions that influenced some differences in their strategies.

By this time, the participants viewed HIV infection or AIDS as a chronic illness, not a disgusting disease, but a company living together and an opportunity of life. They could find the positive changes they had undergone as a result of having HIV or AIDS. HIV/AIDS was now viewed as a friend in their body, who always reminded them to take care of themselves and to be careful in their living. They also perceived positive changes in their lives and their senses of self. These changes included being good persons, avoiding risk behaviors, making merits, having more life experiences, and learning more about the reality of life.

The phenomenon of perceiving benefits in a stressful life event has recently received attention for investigation (Siegel & Schrimshaw, 2000: 1543-1554). It was noted that women with HIV/AIDS reported the positive changes in their lives that they attributed to their illness experiences. These positive changes were identified in a

number of different domains such as health behaviors, spirituality, interpersonal relationships, view of the self, value of life, and career goals. Some of these domains are similar to those that were perceived by the participants in the current study as their positive changes after they had HIV infection.

There is no previous research in Thai culture which reports the positive meaning of HIV infection or AIDS among the infected participants. This may be due to the limited number of investigations of the perception of the disease in Thai participants, who are long-term survival with HIV infection or AIDS. Only one study has noted that HIV-infected women in the northern Thailand accepted their HIV status and viewed their situation in a positive way as an opportunity to plan their lives for the future (Treemanka, 1996: 117-122).

However, there are some studies in the Western countries that have reported the positive perception of the disease among HIV-infected people. These research studies were conducted in people with AIDS who viewed themselves as doing well with the disease (Gloersen and colleagues, 1993: 45-52), with asymptomatic HIV infection who had never been diagnosed with an AIDS-defining illness (Katz, 1996: 52-59), and with long-term nonprogressors with HIV infection (Barroso, 1999: 242-248). These people viewed AIDS as a manageable chronic illness or an opportunity for self-actualization and self-growth. The findings suggested that it required effort, time, and a certain course of actions for HIV-infected participants to gain the positive meaning of HIV infection or AIDS.

The positive perception of the disease and the perception of self and life as normal people led the long-term HIV-infected participants to live, work, and behave as usual as other normal people do. They lived together with families and communities just like normal people. Some lived with partial secrecy, while others lived with complete disclosure of their HIV status. This depended on their work status and their community acceptance. Some participants who were young adults developed their own families. They continued their works to support themselves and their families, and others dedicated themselves to work for other infected people, community, and society.

The competence in managing health and illness and the confidence in living with HIV that these participants had developed since the former stage constituted the

harmonious ways of living with HIV. They were not afraid of HIV anymore and knew how to live healthily, both physically and mentally, with HIV. Finally, the realization of the uncertainty of life made them live carefully and prepare themselves for the terminal illness and death. The preparation and arrangement for the terminal illness and death were individually different depending on their personal values and beliefs.

Consequently, the long-term HIV-infected participants were satisfied with their lives, proud of themselves, and assured of self-worth since they could work and do something useful for their families, other HIV-infected people, community, and society. They lived happily with their families and communities. Moreover, they were ready and felt confident to face the future illness and death.

“Living normally” was similar to the concept of ‘normalization,’ which was identified by Deatrick, Knafl, and Murphy-Moore (1999: 211-212) within the context of family with a chronically ill child. Normalization is defined as a process grounded in the interplay between parents’ definition of the situation and their deliberate efforts to engage in normal parenting and family life activities. It is both a cognitive (defining) process and behavioral (managing) strategies of parents in dealing with having a chronically ill child.

The conceptual components of normalization includes acknowledging the condition and its potential threat to lifestyle, adopting normalcy lens for defining the child and family, engaging in parenting behaviors and family routines that are consistent with normalization, developing a treatment regimen that is consistent with normalcy, and interacting with others based on a view of the child and family as normal. These conceptual components suggest the strategies for parents to normalize family life. According to these strategies, the parents acknowledge the existence of the child’s condition and the need to manage the condition as well as define the family’s life as normal. They pay attention to continue their family’s life as usual, adapt the treatment regimens of the child to achieve a more normalized family life, and interact with other as normal (Deatrick, Knafl, & Murphy-Moore, 1999: 211-212). These parents’ strategies are consistent with the strategies of long-term HIV-infected participants in achieving the state of living normally. These participants accepted their condition, defined self and life as normal people, and lived as usual as it used to be. They lived together with family and community, worked as usual, and

lived in harmony with HIV. Some participants even developed their own family just like ordinary people do.

One strategy in the state of living normally with HIV infection that is not included in the conceptual component of normalization is ‘preparing for terminal illness and death.’ This may be because along the fighting process the long-term HIV-infected people had thought about death for many times. At first, they were so suffered and perceived sooner death, so they made an effort to overcome their suffering by *tham jai*. By the process of *tham jai*, these participants accepted their HIV infection and whatever that would happen in the future, even death. They also *plong/plong tok* by contemplated about death and realized the reality of the uncertainty of life, and then made the decision to let it be. Moreover, they had learned from their own experiences with the illness and other HIV-infected people’s illness and death. This learning always reminded them that they would die someday. Thus, they prepared themselves for the terminal illness and death. Their preparations made them ready to face it and feel released.

The overall process of fighting to live normally was congruent with the two processes of stress and coping identified by Lazarus and Folkman (1984:305), which were cognitive appraisal and coping. Cognitive appraisal is defined as a process through which the person evaluates whether a particular encounter with the environment is relevant to his or her well-being, and, if so, in what way (Lazarus and Folkman, 1984: 31-35). It is continually changing because all encounters with the environment are continually changing and generating feedback. Feedback about the environment, or from one’s own actions and reactions, constitutes new information to be evaluated that is called reappraisal (Lazarus, 1991: 134). In this study, the participants’ perception of HIV/AIDS was changed along the process of fighting to live normally with HIV infection. Their action and interaction strategies in each stage constituted new information and a change in perception that in turn influenced their strategies in the subsequent stage.

Fighting to live normally was a process in which long-term HIV-infected participants continually used both cognitive and behavioral efforts to struggle to live with or overcome their emotional suffering as well as many problems or difficulties in

their lives in order to achieve a state of living normally. The action and interaction strategies, which changed over time along the process and constituted the process, were performed to deal with the specific demands created by HIV infection. This substantive theory, “the process of fighting to live normally with HIV infection”, was in congruence with the coping process described by Lazarus and Folkman (1984: 141-142). However, this middle range theory has been described to understand the coping process of a specific group of people in a specific situation.

When compared with the two major functions of coping: emotion-focused coping and problem-focused coping identified by Lazarus and Folkman (1984: 150-153), the strategies of long-term HIV-infected participants were found to be in both functions of coping. The strategies of these participants in the stage of flight and some strategies in the stage of pulling oneself together to fight were equivalent to emotion-focused coping since these strategies were directed to avoid the situation and to decrease the emotional suffering. The strategies of “finding the meaning in living” in the stage of pulling oneself together to fight and the strategies in the two subsequent stages: fighting for existence and living normally were equivalent to the problem-focused coping.

In addition, the findings revealed that emotion-focused coping was the major strategies in the early period during which long-term HIV-infected participants were overwhelmed with distressed feelings and perceived the disease as a terrible disease. The problem-focused coping strategies began when these participants felt relieved, less fearful, and less anxious. Perception of HIV infection or AIDS in a positive way, realizing self-worth and the worth of life, having willingness to live, and having morale were conditions in performing problem-focused coping strategies.

This research's finding also suggested that long-term HIV-infected participants at various stages with different conditions required different appropriate coping strategies and their coping strategies changed overtime as a process. This suggestion was supported by a number of previous studies, which identified the appropriate coping strategies in various stages of the HIV disease (Côté' & Pepler, 2002: 237; Moneyham, et.al., 1998: 351; Mulder, et.al., 1999: 110-111 ; Rose & Clark-Alexander, 1996: 31-32). Nevertheless, these studies did not identify the

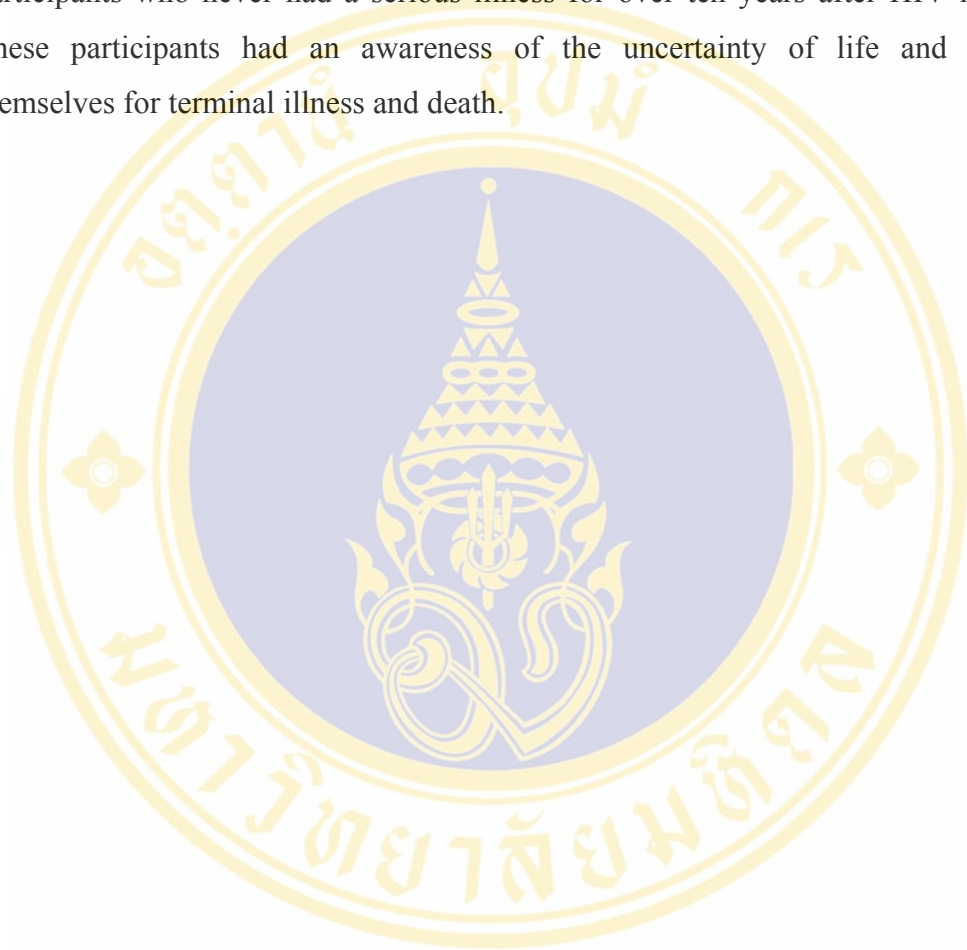
psychological conditions of the HIV-infected people at the time they performed different coping strategies.

A research review on coping of Thai people with HIV/AIDS suggested four consecutive phases of psychological responses: emotional crisis, psychological adjustment, behavioral adjustment, and living with AIDS (Sangchat, 1998: 86-89). The emotional crisis was described as an initial phase that HIV-infected participants felt distressed and still could not adjust their emotions and thoughts. The psychological adjustment was the phase in which these people tried to relieve their psychological distress with various strategies. The behavioral adjustment was the phase in which these people adjusted their behaviors. There were many ways of coping in this phase. Some people used avoidance coping style, whereas some used problem-solving coping style. Finally, the phase of living with AIDS was the phase of progressive HIV diseases. In this phase, people with AIDS needed help, social support, and care from their families or others. This research reviewed the articles studied in various groups of HIV-infected people who were in different stages of the disease.

Comparing to these phases of psychological responses described in the research reviewed, the stage of flight was similar to the emotional crisis stage. The stage of pulling oneself together to fight, in which these participants tried to decrease their emotional distress and found the meaning in living, was equivalent to the psychological adjustment phase. Fighting for existence was similar to the behavioral adjustment phase. The difference was that the actions of long-term HIV-infected participants were mostly directed to solve the problems, while those described in the research review were various coping styles both avoiding and solving problems. This may be due to the fact that the current research was conducted with a specific group of long-term HIV-infected people who represented ones who had successful coping. It also suggested that problem-focused coping might be the effective coping strategies for this stage.

Finally, in the stage of living normally, these participants' strategies were beyond those in the phase of behavioral adjustment and unlike those in the phase of living with AIDS as described in the research review. They did not live with the progressive HIV disease that required help, support, and care. Most of them looked healthy and were able to support themselves. Some participants had a severe

opportunistic infection. Although they felt discouraged and thought of not wanting to live at the time of the illness, they could rebuild their morale shortly afterwards. Then, they sought healthcare, managed the suffering from the illness, and performed self-care until they could recover from the serious illness. However, there were some participants who never had a serious illness for over ten years after HIV infection. These participants had an awareness of the uncertainty of life and prepared themselves for terminal illness and death.



CHAPTER VI

CONCLUSION

In this chapter, the study findings are summarized, then the strengths and limitations of the study are discussed. Finally, the implications for future research and nursing practice, as well as the contributions to nursing knowledge development are presented.

Summary of the Study Findings

The purpose of this study was to develop a substantive theory to explain the coping process of Thai people with long-term HIV infection. The grounded theory was conducted with 20 participants with long-term HIV infection. They were people who had known their HIV seropositivity from serological test for ten or more years ago. The participants consisted of twelve men and eight women. Almost all of them were Buddhist. Their ages ranged from 27 to 52 years with the average age of 38 years. The period of time that the participants were aware of their HIV status ranged from ten to 16 years. The majority of the participants had been aware of their HIV infection for ten years, and they contracted the virus through heterosexual contacts. Twelve participants had experienced the HIV-related diseases, while the other eight never had. The participants' CD₄ levels were widely different, ranging between 1 and 800 cells/ μ l. Three participants had CD₄ levels above 500 cells/ μ l.

The core category emerging from data analysis was the process of fighting to live normally with HIV infection. It was the process that the participants continuously pushed both cognitive and behavioral efforts to struggle against or overcome their suffering as well as many problems or difficulties in their lives, which were created from having HIV infection, in order to achieve a state of "living normally". "Living normally" was a state in which the participants perceived themselves and went on with life as ordinary persons in the society. The process of fighting to live normally

consisted of four consecutive stages: flight, pulling oneself together to fight, fighting for existence, and living normally.

Stage 1, flight, began after long-term HIV-infected participants knew their HIV infection and they perceived the infection as a terrible disease that was incurable, caused of sooner death, and was disgusting. They were overwhelmed with distressed feelings including sadness, hopelessness, fear, and anxiety. The social contextual conditions in those days were the generalized negative social images of HIV infection or AIDS and negative social reactions to HIV-infected persons. The use of the “Monitoring and Controlling Patients Who Caught Serious Infectious Disease” Act 1985 in Thailand during the years 1985 to 1989 was another social context which reflected the great fear of the society toward HIV-infected people.

In the conditions of perceiving HIV infection or AIDS as a terrible disease and being overwhelmed with distressed feelings within these social contexts, the participants avoided facing the problems or the situations related to their HIV infection. They kept their HIV status secret and avoided social contact. Some had to leave their home, and others were unwilling to live. Their strategies and the time they consumed in the flight stage seemed to depend on certain intervening conditions of the healthcare system that they experienced and their family system. Consequently, they suffered, and some had to encounter the difficulties in living.

Stage 2, Pulling oneself together to fight, was a transitional stage in which long-term HIV-infected participants turned themselves from flight to fighting, or from avoiding the situation related to HIV infection to encountering it. The sufferings and the realization of sooner death that had been occurred since the former stage became the conditions of these participants at the time, when they moved into this stage. Their conditions pushed them to seek help from their family, health centers or healthcare providers, HIV-infected friends or groups, and respected spiritual matters. They made efforts to overcome their distressed feelings by alleviating the feelings and ‘*tham jai*,’ as well as to find the meaning in living.

Tham jai was a process of mental work to adjust, or to control one’s thoughts and feelings. In this study, it was the process in which the participants tried not to think about their situations, thought positively, accepted their situations, and *plong/plong tok*. *Plong/plong tok* is a process of thinking that begins with

contemplating about life and death, followed by realizing the reality of the uncertainty of life, and then making a decision to let it be. Finding the meaning in living was a strategy which the participants used to search for what was significant in their lives and made a decision about how to live or what to be done in the rest of their lives. They realized their self-worth and the worth of life, and then created a purpose of life.

The intervening conditions that facilitated these participants' strategies in this stage were social supports, healthcare providers, and some personal attributes. The participants' strategies in pulling themselves together to fight not only made them experience relief and have some changes in their perception about HIV infection or AIDS but also constituted a ready state to fight for living. It was a state in which they realized their self-worth and the worth of life, and also have a will to live, a hope, morale, and a purpose in living.

Stage 3, fighting for existence, was a stage in which long-term HIV-infected participants worked very hard to overcome many events or difficulties to continue their family's and their own lives, as well as to attain their purposes in living. The social contextual conditions during those time were the generalized social discrimination and prejudice against people with HIV. However, there were HIV-infected groups and social organizations working on HIV/AIDS which gradually developed in Thai society. These groups and organizations provided support to these participants.

The consequences that happened in the former stage were the important conditions in entering this stage. These conditions were the perception of the possibility of years to live, realization of self-worth and the worth of life, having willingness to live, having morale and having purposes in living. With these conditions, they were strengthened enough to fight for their lives and their families. Their strategies in this stage included seeking fundamental factors for living, learning about HIV/AIDS, managing health and illness, keeping up morale, as well as concealing and disclosing their HIV-infection as they saw appropriate. The problems that the participants encountered, social support, as well as personal resources and attributes were the intervening conditions that influenced these strategies.

The long-term HIV-infected participants sought the fundamental factors for their family's and their own living by mobilizing resources, finding jobs, and working

hard. Afterwards, they could meet their basic physical needs and could support themselves and their families. Therefore, they had more sense of self-worth, felt proud of themselves, and became more satisfied with life. Their perception about HIV infection or AIDS had much changed through their learning and managing their health and illness. They viewed HIV/AIDS in a more positive way. They also developed competence in managing health and illness and the confidence in living with HIV. These consequences were the conditions that moved these participants into the next stage, the stage of living normally.

Stage 4, living normally, is a state in which long-term HIV-infected participants perceived themselves and went on with life as ordinary persons in the society. The conditions that led them to this stage were the perception of HIV/AIDS in a positive way, perception of self and one's life as normal people, the competence in managing health and illness, the confidence in living with HIV, and the realization of the uncertainty of life. They viewed HIV infection or AIDS as a chronic illness, not a disgusting disease, but a company living together, and an opportunity of life. They perceived positive changes in their lives and their senses of self, such as being good persons, quitting risk behaviors, making merit, having more life experiences, and learning more about the reality of life. The social context during this time had much changed. HIV-infected groups, organizations, and network were fully developed, and the communities had more understanding of HIV-infected people.

The positive perception of the disease and the perception of self and life as normal people led the participants to live together with families and communities, and to work just like normal people. Some participants developed their own families. The competence in managing health and illness and the confidence in living with HIV constituted the harmonious way in living with the disease. In addition, they prepared themselves for terminal illness and death because they realized that their lives were uncertain. Personal factors and the community's acceptance of HIV-infected people were the intervening conditions that influenced some differences in their strategies. Consequently, they felt satisfied with their lives, happy, proud of themselves, and assured of their self-worth. Moreover, they were confident and ready to face the future illness and death.

Strengths of the Study

The strength of this study is that it generates a mid-range theory that can guide nursing practice. The findings of the study bring out the coping process of people who could live long with HIV. The strategies these individuals performed as well as the causal and intervening conditions that influence their strategies are demonstrated. The consistency among the findings and the existing theories or the previous studies made additional strength to the study. These findings can be useful for nurses and health personnel in providing care and counseling to HIV-infected people and their families.

The methodological technique of member check added strength to the credibility of the research findings. The data and the interpretations of the data were validated with the participants in every next interview. Moreover, the interpretation and conclusion of the study were tested with some participants and a social worker who had worked for HIV-infected people for more than ten years.

The contributions of the participants in the study strengthened the research findings. They were willing to share their experiences since they thought that their experiences might be useful for other HIV-infected people. They enthusiastically gave additional information, as well as comments and suggestions to the data, interpretations, and analytic categories emerging from the interviewed data. Finally, the participants of the study consisted of long-term HIV-infected people with different backgrounds and characteristics in terms of age, gender, marital status, educational background, socioeconomic status, the history of HIV-related disease, and the history of anti-retroviral therapy.

Limitations of the Study

The limitations of this study related to the characteristics of the participants and the methodological procedures. The participants were people who had known their HIV-seropositivity from serological test for ten or more years. The investigator could not confirm the date of HIV infection diagnosis of some participants. Therefore, for these participants, the data had to rely on their subjectivity. However, most of

them had recommendations from others, such as nurses, social workers, counselors, or other HIV-infected people, that they had been infected with HIV for over ten years.

The participants of the study were limited to the people who did not have a severe HIV-related illness that required hospitalization or care from others at the time of the interview. If long-term HIV-infected people were in the time of severe illness, they may have some different perceptions and interpretations of their experiences. Finally, the Buddhist teaching which exists in Thai culture influenced the strategies these individuals performed in their coping process. Therefore, the long-term HIV-infected people in other religions or other culture may have different strategies.

As for the methodological limitation, the results of the study were mainly drawn from the interview data obtained from the long-term HIV-infected individuals. The validity of the data could have been enhanced if the interview data had been gathered from their family members and friends who were aware of their infection, as well as the medical records of their history of HIV-related diseases, anti-retroviral medications, and laboratory tests. In this study, the investigator had opportunities to talk with the family members of only few participants and was unable to review the medical records of some participants.

Implications for Future Research

The findings of this study have delineated the process of fighting to live normally of long-term HIV-infected people. The process began when these people were aware of their HIV infection until they could live normally like other ordinary people. The findings can be a guideline for the development of nursing practice to promote the effective coping of HIV-infected people since the time they were firstly informed of the diagnosis. The intervention program based on the study findings should be developed and future research should be aimed to evaluate the effectiveness of the program. It is also imperative that the measurement for the variables, which will be used as the evaluative criteria, be firstly developed. The evaluative criteria may be the perception of the disease, the distressed feelings, morale, sense of self-worth and the worth of life, as well as the health status. The measurement of these variables should be developed in the cultural relevance from the studied population.

Apart from the process of fighting to live normally with HIV infection, the long-term HIV-infected participants underwent some sub-processes including *tham jai*, *plong/plong tok*, finding the meaning in living, and keeping up morale. These processes were crucial for overcoming their distressed feelings, creating a purpose of life, and maintaining their health. Thus, these processes should be further explored in the future research. Knowledge about these processes in these individuals would be useful for nurses to provide counseling services as well as the facilitative and supportive environment to assist HIV-infected people.

Furthermore, some suggestions of the study findings should be tested by quantitative studies. The personal attributes of persistence and fighting spirit, which are similar to the control component of hardiness personality and manageability component of the sense of coherence, are suggested as conditions facilitating the long-term HIV-infected individuals' strategies in living through their various and severe difficulties in life. These attributes may account for their healthy status for a long time in spite of HIV infection. The concept of hardiness or a sense of coherence may be applied for the measurement of these attributes and the longitudinal study should be carried out to follow up on the outcomes.

Besides, the study findings suggested that HIV-infected individuals at various stages with different conditions required different appropriate coping strategies and the coping strategies change overtime as a process. During the time that HIV-infected people were overwhelmed with distressed feelings, their strategies usually aimed to relieve their emotional distress. On the other hand, the feeling of relief, realization of self-worth and the worth of life, the will to live, and morale were their conditions for performing problem-solving strategies. This suggestion remains to be validated in further studies.

Implications for Nursing Practice

A major contribution of this study to nursing practice is that it offers a new insight into the coping process of long-term HIV-infected people which is called the process of fighting to live normally. The findings could be used as a guideline for developing the nursing intervention program to provide care to HIV-infected people.

The nursing intervention program should be a course of continual nursing actions that would be adjusted to the dynamic conditions of the HIV-infected people. The nursing objectives and nursing interventions should be as follows:

1) To relieve the distressed feeling of the HIV-infected individuals

The findings reveal that after the HIV-infected people know the diagnosis, they are overwhelmed with distressed feelings. They keep their HIV status secret and isolate themselves. They are unable to gain access to social support because most of them still cannot tell anyone about their HIV status. Some of them may entertain a suicidal thought. During this period, these people are in particular need of help and support. The nursing interventions should aim to relieve the distressed feelings of these people.

Healthcare providers are usually the persons whom the HIV-infected people meet immediately after they know their HIV status. The findings point out that the healthcare system is one intervening condition influencing the long-term HIV-infected individuals' strategies and the time they consume in the flight stage. The findings also indicate that the healthcare system could decrease HIV-infected individuals' distressed feelings and the suicidal incidence. Healthcare providers therefore should assure confidentiality, inform the HIV-blood test result personally to the infected person, as well as provide the information about the disease and counseling to the HIV-infected people.

Confidentiality is a basic prerequisite for building trust relationships between an HIV-infected individual and a healthcare provider within the counseling process (Sauka & Lie, 2000: 737). Nurses and healthcare providers should be more aware of the possibility of unintended disclosure of the individuals' HIV status by their actions. Nurses should not assume that the infected individuals' spouses, family members, closed relatives and friends, who accompany them to the hospital, are aware of their infection.

The findings of this study could also be helpful to the provision of information and counseling services to the HIV-infected people. The evidence in the study suggests that healthcare providers should provide the following information to the infected people: "you can live long if you take care of yourself," "you can live with other people because the disease cannot easily be transmitted to others and others

cannot know your HIV status unless you tell them,” and “there are several HIV-infected groups and organizations that you can access for help.” This information would help them get rid of some fear and anxiety and make some positive changes in their perception of HIV/AIDS.

Another suggestion of this study is that the acceptance of the family and the encouragement from the family and HIV-infected friends are significant in decreasing the distressed feelings of the HIV-infected people. Therefore, nurses should create or facilitate this supportive environment for these individuals by providing guidance and counseling to the families as well as developing the HIV-infected groups in the health centers or promoting the development of these groups in the community. The families should know not only the same information as the HIV-infected individuals should but also their roles in supporting these individuals. However, providing guidance and counseling to the families should be done only in the cases that the infected individuals have disclosed their infection to the families. The development of the HIV-infected groups in the health centers and the community would be helpful for the infected people since they are able to share their feelings and experiences to one another, encourage one another, and give reciprocal support to one another. Nurses should encourage the infected individuals especially ones who are newly diagnosed to join these groups.

2) To encourage the HIV-infected individuals in realizing the worth of self and life, and also creating a purpose of life

The findings of the study point out that *tham jai* and finding the meaning in living are processes in which the HIV-infected people engage for relief of their distressed feelings, realization of self-worth and the worth of life, and having a purpose in living. Nurses and healthcare providers should encourage them to undergo these two processes through the counseling process. Nurses might need to learn how to examine and be aware of these individuals' values, beliefs, and perceptions of HIV/AIDS because these are the conditions that influence the process of *tham jai* and finding the meaning in living. Buddhist teaching might be applied for the persons who believe in it. Nurses might discuss with them about what are significant to them and what they would like to do in their lives. The discussion would encourage them in realizing the worth of themselves and life, and also creating a purpose in life. With the

conditions of feeling relief, realizing self-worth and the worth of life, and having a purpose in life, the HIV-infected people are ready to fight for their existence.

3) To provide knowledge about the HIV disease and its management to the HIV-infected people

The research findings indicate that learning about HIV/AIDS can change the HIV-infected people's perception about the disease in a positive way. They can develop the competence in managing health and illness and confidence in living with HIV, which are the conditions of the individuals to constitute a stage of living normally. Nurses should provide the HIV-infected individuals with the knowledge about the disease including the nature of the disease, the factor affecting the disease progression, and the management of their health and illness. Nurses should apply both medical science and human experiences in living with HIV/AIDS for the provision of this knowledge.

4) To provide healthcare and support to the HIV-infected people

In the course of living with HIV/AIDS, sometimes the individuals are sick or encounter with the difficulties and are in need of healthcare and support. Nurses and healthcare providers should assess their conditions, provide care for ones in needs, encourage the families or their significant persons to give them moral supports, and co-operate with the social organization or the NGOs working on AIDS activities to provide further supports to them. The care and supports these individuals receive will make them realize that they are still worthy for others and keep going their lives through the difficult situations.

5) To raise the community's and society's awareness of HIV infection and AIDS

Nurses should educate people and community to raise the community's and society's awareness of HIV infection and AIDS. This awareness will increase the community's understanding of HIV-infected people and also the community's and society's acceptance to these people. The community's and society's understanding and acceptance are the conditions that facilitate the normal living of the HIV-infected people.

Contribution to Nursing Knowledge Development

This qualitative research using grounded theory generates a mid-range theory entitled “The process of fighting to live normally with HIV infection.” This mid-range theory focuses on a specific phenomenon, “the coping process of HIV-infected Thai people who can live long.” The theory describes how long-term HIV-infected Thai people cope with the problems or events related to the infection and delineated their coping as a process that these people have passed through since they first learned of their infection. The theory demonstrates the human potential in living with the incurable HIV disease. Along the coping process the long-term HIV-infected Thai people can develop a competency in managing health and illness. Ultimately, they can live in harmony with HIV. They can work for families’ and their own living. Consequently, they are satisfied with their lives, happy, proud of themselves, and assured of their self-worth.

This mid-range theory is consistency with nursing perspectives. The phenomenon described in the theory is a phenomenon of nursing concern since it is related to the health-illness quality of human condition. Nursing concerns with a person’s well-being and more-being, as well as helping him become more as humanly possible in his particular life situation. The goal of nursing in helping persons with terminal, hopeless, or chronic illness is not the absence of the disease, but it is their well-being and their potential with the illness (Paterson & Zderad, 1976: 11-12).

Additionally, the theory reflects the holistic philosophy of person, health, and healing. The causal conditions, intervening conditions, action/interaction strategies, and consequences that bring out the coping process of long-term HIV-infected people clearly demonstrate the inter-relationships of the bio-psycho-social-spiritual dimensions of person and health, and the continual interaction between person and environment. These are consistent with the two views regarding holism of holistic nursing: 1) identifying the inter-relationships of the bio-psycho-social-spiritual dimensions of the person; and 2) understanding that the individual as a unitary whole in mutual process with the environment (Dossey, 2001: 1).

According to the holistic philosophy of health and healing which is based on “The Law of Similars”, health is the balanced integration of all the factors that

surround and make up the individual person. Illness is the result of a disturbance in the vital force, and symptoms are evidence that the physis is attempting to restore balance, to cure itself, to self-correct. The law of similars holds that curing is effected by assisting the physis to do the work it has already started. Holistic treatment honors the patient's subjective experience and intelligence and includes a profound respect for the self-healing capacities within the individual (Light, 1997: 29-31). The findings of the current study reveal some individuals' experience of self-healing with HIV-disease and suggest that the role of healthcare provider is to create the environment to facilitate the healing process of HIV-infected individual.

This mid-range theory gives nurses directions to help HIV-infected people achieve their wellness and develop their potential with the illness. The causal conditions, the intervening conditions, and the action/interaction strategies of these individuals described in each stage of the process can guide the development of nursing intervention program to provide or to facilitate the supportive environment or conditions to promote their coping process, their health and wellness.

In addition, some sub-processes including *tham jai*, *plong/plong tok*, finding the meaning in living, and keeping morale up were found to be crucial in the process of fighting to live normally with HIV infection. The description of these sub-processes in the theory can be also applied for counseling to HIV-infected people. However, the knowledge regarding the conceptualization of these sub-processes should be further developed by means of the qualitative research that brings out the rich description and explanation of these processes in varying populations of life-threatening chronic illness within Thai cultural groups.

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ศาสตร์และมนุษยศาสตร์ มหาวิทยาลัยมหิดล.



APPENDIX A1

The Personal and HIV-related Information Sheet

ID _____ Date _____

Direction: The following information will be obtained from an interview with the participant by the investigator and from the medical records.

Biographic and socio-cultural information

Sex: male female

Age: _____

Place of living (province) _____

Education level:

Primary school (Pratom 1 to 6)

Secondary school (Mathayom 1 to 6)

Vocational school

Bachelor degree

Master degree

PhD.

Religion:

Buddhist

Christian

Islamic

Others (specify) _____

Occupation _____

Marital status:

Single

Married, no. of years _____

Divorced, no. of years _____

Separated, no. of years _____

Widowed, no. of years _____

Number of children _____

Children's age _____, _____, _____, _____, _____

Number of people in the household _____

Status or role in the family (can answer more than one)

Mother / Father

Wife / Husband

Daughter / son

Others _____

Household income/month _____

Adequate for living expenses

Inadequate for living expenses

Being member of / joining activities with groups

No

Yes (identify the group, role, activities)

HIV infection related information

HIV infection diagnosis date _____ Hospital / Clinic _____

Route of HIV infection

Homosexual

Heterosexual from _____

Injection drug use

Blood transfusion

Others _____

Don't know

Disclosure of HIV status No Yes, to _____

History of anti-retroviral therapy

Laboratory tests (Hematology, Serology, and viral detection)

History of HIV-related diseases

No

Yes (identify)

APPENDIX A2

The Personal and HIV-related Information Sheet (Thai Version)

ข้อมูลส่วนบุคคลและข้อมูลเกี่ยวกับการติดเชื้อเอชไอวี

รหัส _____ วันที่ _____

คำชี้แจง ข้อมูลต่อไปนี้ได้จากการสัมภาษณ์ผู้ป่วย และบันทึกทางการแพทย์

ข้อมูลส่วนตัว

เพศ: ชาย หญิง อายุ _____ ปี

อาศัยอยู่ในจังหวัด _____

ระดับการศึกษา:

ประถมศึกษา

ปริญญาตรี

มัธยมศึกษา

ปริญญาโท

อาชีวศึกษา

ปริญญาเอก

ศาสนา:

พุทธ

คริสต์

อิสลาม

อื่นๆ (ระบุ) _____

อาชีพ: _____

สถานภาพสมรส

โสด

คู่ จำนวนปี _____

แยก จำนวนปี _____

หย่า จำนวนปี _____

ม่าย จำนวนปี _____

จำนวนบุตร / ธิดา _____ อายุ _____, _____, _____, _____, _____, จำนวน

สมาชิกในครัวเรือน _____

บทบาทของท่านในครอบครัว (ตอบได้มากกว่าหนึ่งข้อ)

แม่ / พ่อ

ภรรยา /สามี

ธิดา / บุตร

อื่นๆ (ระบุ) _____

รายได้ของครอบครัวต่อเดือน _____

เพียงพอสำหรับค่าใช้จ่าย

ไม่เพียงพอสำหรับค่าใช้จ่าย

การเป็นสมาชิก / การเข้าร่วมกิจกรรมกลุ่ม

ไม่มี

มี (ระบุ ชื่อกลุ่ม บทบาทในกลุ่ม และกิจกรรมที่ทำ)

ข้อมูลเกี่ยวกับการติดเชื้อเอชไอวี

วันที่ของการวินิจฉัยการติดเชื้อเอชไอวี _____ จากโรงพยาบาล / คลินิก _____

ติดเชื้อเอชไอวีจาก

การรักร่วมเพศ

การมีเพศสัมพันธ์ (ต่างเพศ) กับ _____

ยาเสพติดชนิดฉีด

การได้รับเลือด

อื่นๆ (ระบุ) _____

ไม่ทราบ

การเปิดเผยการติดเชื้อเอชไอวีของตนต่อผู้อื่น

ไม่เปิดเผย

เปิดเผย กับ _____

ประวัติการได้รับยาต้านไวรัส

ผลการตรวจทางห้องปฏิบัติการ

ประวัติการเจ็บป่วยด้วยโรคที่สืบเนื่องจากเชื้อเอชไอวี

ไม่มี

มี

APPENDIX B1

Interview Guide

Interview Questions

1. Tell me what have happen to you since you have known you are infected with HIV.
2. How did you feel and think when you were first told that you had been infected with HIV?
3. How do you feel and think about HIV infection at that time?
4. How do you feel and think about yourself as being HIV-infected person at that time?
5. In what ways do you deal with your feelings, and thought at that time?
6. How do you feel and think about your life after HIV infection?
7. Have your feelings and thought about HIV infection, yourself, and your life changed since you were infected with HIV? How and when do they change?
8. What make your feelings and thought about HIV infection, yourself, and your life change?
9. How did HIV-infection affect your life? What problems or events have occurred to you? (body, feelings, thought, emotion, activities, relationships with others, roles, etc.)
10. In what ways do you deal with the problems or the events you have regarding your HIV-infection?
11. What help you to deal with your feelings, thought, problems or events relating to HIV-infection? (Person or group of persons, material, inner resources, etc.) How do they work or help?
12. What are the obstacles to you in managing the problems or events related to HIV-infection? How do they impede the management of the problems or events related to HIV-infection?

The last open-ended question

Is there anything about your experiences of living with HIV infection that you would like to share more?

APPENDIX B2**Interview Guide (Thai version)****แนวคำถามสำหรับการสัมภาษณ์****คำถามสำหรับการสัมภาษณ์**

1. กรุณาเล่าให้ฉันฟังว่า มีอะไรเกิดขึ้นกับคุณบ้างตั้งแต่คุณรู้ว่าคุณติดเชื้อเอชไอวี
2. คุณคิดและรู้สึกอย่างไรเมื่อแรกทราบว่าติดเชื้อเอชไอวี
3. คุณคิดและรู้สึกอย่างไรเกี่ยวกับการติดเชื้อเอชไอวีในขณะนั้น
4. คุณคิดและรู้สึกต่อตนเองอย่างไรที่เป็นผู้ติดเชื้อเอชไอวีในขณะนั้น
5. คุณจัดการกับความรู้สึก และความคิดที่เกิดขึ้นในขณะนั้นอย่างไร
6. คุณคิดและรู้สึกต่อชีวิตของตนเองอย่างไรหลังการติดเชื้อเอชไอวี
7. ความคิดและรู้สึกของคุณต่อการติดเชื้อเอชไอวี ต่อตนเอง และต่อชีวิตของคุณมีการเปลี่ยนแปลงหรือไม่นับตั้งแต่คุณติดเชื้อ การเปลี่ยนแปลงนั้นเกิดขึ้นเมื่อไร และเปลี่ยนแปลงอย่างไร
8. อะไรทำให้ความคิดและรู้สึกของคุณต่อการติดเชื้อเอชไอวี ต่อตนเอง และต่อชีวิตเปลี่ยนแปลง
9. การติดเชื้อเอชไอวีมีผลต่อชีวิตของคุณอย่างไร เกิดปัญหาหรือการเปลี่ยนแปลงอะไรกับคุณบ้าง (ร่างกาย ความคิด ความรู้สึก การทำกิจกรรมต่างๆ ความสัมพันธ์กับผู้อื่น บทบาท และอื่นๆ)
10. คุณจัดการกับปัญหา หรือการเปลี่ยนแปลงที่เกิดขึ้นจากการติดเชื้อเอชไอวีอย่างไร
11. อะไรบ้างที่ช่วยคุณในการจัดการกับปัญหาหรือการเปลี่ยนแปลงที่เกิดจากการติดเชื้อเอชไอวี (บุคคล กลุ่มบุคคล ปัจจัยทางวัตถุ แหล่งประโยชน์ภายในตน และอื่นๆ) สิ่งเหล่านี้ช่วยเหลือคุณอย่างไร
12. อะไรบ้างที่เป็นอุปสรรคต่อคุณในการจัดการกับปัญหาหรือการเปลี่ยนแปลงที่เกิดจากการติดเชื้อเอชไอวี สิ่งเหล่านี้เป็นอุปสรรคอย่างไร

คำถามปิดกว้างสุดท้าย

คุณมีประสบการณ์เกี่ยวกับการมีชีวิตอยู่กับการติดเชื้อเอชไอวีที่อยากจะเล่าให้ฉันฟังเพิ่มเติมอีกไหมคะ

APPENDIX C1

Consent Form

Coping Process of Long-term HIV-infected Thai People

Investigator: Rachanee Namjantra, R.N., M.Sc. (nursing)
Doctoral student, Faculty of Nursing, Mahidol University
2 Prannok Road, Bangkoknoi, Bangkok 10700
Tel. (02) 322-9603 (home)

Investigator's Statement

I am asking you to be involved with a research study. This study is a part of my graduate studies in nursing at Mahidol University. The purpose of this consent form is to give you the information you will need to help you decide whether or not to be in the study. Please read the form carefully. You may ask any questions about the research or this form that is not clear. When all of your questions have been answered, I will ask if you want to be in the study or not. Your participation in this study is voluntary, so you may say yes or no.

Purpose and Benefits

The purpose of this study is to describe how long-term HIV-infected Thai people cope with HIV-infection and the problems, changes, or life events happen in their lives related to HIV-infection. The benefit of the study will be an understanding of the experience of dealing with HIV-infection among long-term HIV-infected Thai people. The information you share will enable nurses and other health care providers to offer better care and support for HIV-infected people and AIDS patients.

Procedures

I would ask you to be in some interviews, in a place of your choice, about your experiences in coping with HIV infection. During the interviews, you will be asked about your personal information, such as education, occupation, marital status, your family, and your history of HIV infection. You will also be asked with open-ended questions, which will explore your feelings and thought about HIV infection; the problems, the changes, or the events happen in your lives related to HIV infection; and how you cope with HIV infection, and the problems, the changes, or the events. The interview will be taken at least twice of one to two hours. During the interview, you can ask questions, refuse to answer any questions you do not want to discuss, or stop the interview at any time you want. The interview will continue only when you desire. In the second or next interview, I will summarize the data and the interpretation of the previous interview to you. If you disagree with the data or the interpretation, you can correct them and also give me additional information. You will also be asked some more questions that have not been discussed in the previous interview and some questions for clarifying some of the previous information. I will

also ask to look at your medical record to confirm the date of HIV infection diagnosis; and review your history of HIV-related diseases, anti-retroviral medications, and laboratory tests.

Risk, Stress, or Discomfort

Some of the questions asked might make you feel sad, anxious, or upset. You may find it difficult or painful to talk about your private feelings that you do not often discuss with others. However, having an opportunity to talk about your stressful experiences could be helpful in working through your feelings. You are free not to answer the questions and to withdraw from the study at any time. The interview can be stop at any time you want.

Other Information

The interviews will be audiotape-record with your permission and transcribed by me into written form. All of the information you provide will be confidential. Your name will not be attached to the audiotapes, and will not be used on any interview form. Your name will be replaced with code number. I am the only one person who knows your actual identity. Other identifiers such as institution or place will be removed from the transcripts. The audiotapes will be stored in a locked cabinet and will be erased upon completion of the study. The transcripts, and your name and address will be kept in a separate locked file and will be available only to me. The results of the study will be reported as groups and will not include any identifying data. You will be given 200 Bahts in cash as compensation for your time and participation in the study although you may decide to discontinue or withdraw during the interview.

Signature of investigator

Date

Participant's Statement

The study described above has been explained to me. I voluntarily consent to participate in this study. I have had an opportunity to ask questions. I understand that if I have questions later on about the research and my rights as a participant in this study, I may receive the answers from the investigator. I give permission to the investigator to use my medical records as described in this consent form. I will receive a copy of this consent form.

Signature of participant

Date

Copies to: Participant
Investigator's file

APPENDIX C2

ใบยินยอมการเข้าร่วมการวิจัย

เรื่อง กระบวนการเผชิญปัญหาของผู้ติดเชื้อเอชไอวีชาวไทยที่มีชีวิตยืนยาว

ผู้วิจัย รชนี นามจันทร์ วท.ม. (พยาบาล)
นักศึกษาระดับปริญญาโท สาขาพยาบาลศาสตรดุษฎีบัณฑิต
คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล
2 ถนนพราณอก เขตบางกอกน้อย กรุงเทพฯ 10700
โทร (02) 322-9603 (บ้าน)

คำแถลงของผู้วิจัย

ดิฉันจะขอเชิญคุณเข้าร่วมการวิจัย การวิจัยนี้เป็นส่วนหนึ่งของการศึกษาในหลักสูตรพยาบาลศาสตรดุษฎีบัณฑิต มหาวิทยาลัยมหิดล ใบยินยอมนี้มีวัตถุประสงค์เพื่อให้ข้อมูลแก่คุณ ซึ่งคุณจำเป็นต้องใช้ในการตัดสินใจว่าคุณจะเข้าร่วมในการวิจัยหรือไม่ กรุณาอ่านใบยินยอมนี้โดยละเอียด คุณสามารถถามคำถามต่างๆเกี่ยวกับงานวิจัยหรือใบยินยอมนี้ที่ยังไม่ชัดเจน เมื่อดิฉันตอบคำถามของคุณหมดแล้ว ดิฉันจะถามคุณว่า คุณต้องการเข้าร่วมงานวิจัยนี้หรือไม่ การเข้าร่วมงานวิจัยของคุณจะเป็นไปด้วยความสมัครใจ คุณสามารถตอบรับหรือปฏิเสธก็ได้

วัตถุประสงค์และประโยชน์ของงานวิจัย

การวิจัยนี้มีวัตถุประสงค์เพื่อที่จะบรรยายว่าผู้ติดเชื้อเอชไอวีชาวไทยที่มีชีวิตยืนยาวเผชิญหรือจัดการกับการติดเชื้อเอชไอวี และปัญหาหรือการเปลี่ยนแปลงหรือเหตุการณ์ที่เกิดขึ้นในชีวิตซึ่งเป็นผลจากการติดเชื้อเอชไอวี ไร ประโยชน์ที่จะได้รับจากการวิจัยครั้งนี้คือ ความเข้าใจเกี่ยวกับประสบการณ์การจัดการกับการติดเชื้อเอชไอวีของผู้ติดเชื้อเอชไอวีชาวไทยที่มีชีวิตยืนยาว ข้อมูลที่คุณให้จะช่วยให้พยาบาลและบุคลากรที่ให้บริการทางด้านสุขภาพสามารถให้การดูแลและช่วยเหลือสนับสนุนผู้ติดเชื้อเอชไอวี และผู้ป่วยเอดส์ได้ดีขึ้น

ขั้นตอนของการวิจัย

ดิฉันจะขอพบและพูดคุยสัมภาษณ์คุณในสถานที่ที่คุณเลือก การพูดคุยจะเกี่ยวข้องกับประสบการณ์ของคุณในการจัดการกับการติดเชื้อเอชไอวี ในการสัมภาษณ์ดิฉันจะสอบถามเกี่ยวกับข้อมูลส่วนบุคคลของคุณ เช่น การศึกษา อาชีพ สถานภาพสมรส ครอบครัว และประวัติการติดเชื้อเอชไอวี และจากนั้นจะถามคุณด้วยคำถามปลายเปิด ซึ่งจะสอบถามเกี่ยวกับความคิดและความรู้สึกของคุณเกี่ยวกับการติดเชื้อเอชไอวี ปัญหาหรือเหตุการณ์ที่เกิดขึ้นในชีวิตซึ่งสืบเนื่องจากการติดเชื้อเอชไอวี ตลอดจนการจัดการกับการติดเชื้อเอชไอวี และปัญหาหรือเหตุการณ์ที่เกิดขึ้นอื่นๆ การพูดคุยสัมภาษณ์จะมีขึ้นอย่างน้อย 2 ครั้ง แต่แต่ละครั้งใช้เวลาประมาณ 1-2 ชั่วโมงระหว่างการสัมภาษณ์คุณสามารถถามคำถามที่คุณสงสัยเกี่ยวกับการวิจัยและสิทธิของคุณ คุณสามารถปฏิเสธการตอบคำถามใดๆที่คุณไม่ต้องการจะตอบ และสามารถขอหยุดการสัมภาษณ์เมื่อคุณต้องการ การสัมภาษณ์จะดำเนินต่อไปก็ต่อเมื่อคุณต้องการ การสัมภาษณ์ครั้งที่สองหรือครั้งต่อไป ดิฉันจะสรุปข้อมูลและการแปลความหมายข้อมูลจากการพูดคุยครั้งก่อนให้คุณฟัง หาก你不เห็นด้วยกับข้อมูลหรือการแปลความหมายข้อมูลนั้น คุณ

สามารถแก้ไขข้อมูลให้ถูกต้อง และให้ข้อมูลแก่ดิฉันเพิ่มเติม ดิฉันอาจจะขอสอบถามคุณเพิ่มเติมในประเด็นคำถามที่ยังไม่ได้พูดคุยกัน หรือเพื่อเพิ่มความเข้าใจหรือความชัดเจนของข้อมูลที่พูดคุยกันในครั้งก่อน นอกจากนี้ ดิฉันจะต้องขอฉบับที่กทางการแพทย์ของคุณเพื่อยืนยันวันที่คุณได้รับการติดเชื้อและบันทึกข้อมูลเกี่ยวกับประวัติการเจ็บป่วยด้วยโรคที่สืบเนื่องจากเชื้อเอชไอวี การได้รับยาต้านไวรัส และผลการตรวจทางห้องปฏิบัติการ

โอกาสที่จะเกิดความเสียหาย ความเครียดหรือความไม่สุขสบาย

คำถามบางคำถามอาจทำให้คุณรู้สึกเศร้าใจ วิตกกังวล หรืออารมณ์เสีย คุณอาจรู้สึกว่ามันเป็นสิ่งที่ยากลำบากและเจ็บปวดที่จะพูดคุยถึงความรู้สึกส่วนตัวซึ่งคุณไม่ค่อยพูดให้คนอื่นฟัง อย่างไรก็ตามการมีโอกาสพูดคุยเกี่ยวกับประสบการณ์ที่ตึงเครียดของคุณอาจช่วยให้คุณรู้สึกดีขึ้น คุณมีอิสระที่จะไม่ตอบคำถามหรือถอนตัวจากการวิจัยเมื่อใดก็ได้ และการสัมภาษณ์สามารถจะหยุดเมื่อใดก็ได้ที่คุณต้องการ

ข้อมูลเพิ่มเติม

ดิฉันจะบันทึกการพูดคุยสัมภาษณ์ด้วยเทปบันทึกเสียงและถ่ายถอดเนื้อหาของการสนทนาในเทปลงบนกระดาษโดยตัวดิฉันเอง ข้อมูลทั้งหมดที่คุณให้จะถูกเก็บรักษาไว้เป็นความลับ ชื่อของคุณจะไม่ปรากฏบนแบบฟอร์มใดๆของการสัมภาษณ์หรือเชื่อมโยงถึงเทปบันทึกการสัมภาษณ์ ชื่อของคุณจะถูกแทนที่ด้วยรหัสที่เป็นตัวเลข ซึ่งดิฉันเพียงคนเดียวเท่านั้นที่ทราบข้อมูลที่บ่งชี้ถึงตัวคุณ ข้อมูลที่บ่งชี้ถึงตัวบุคคล เช่นชื่อสถาบันหรือสถานที่จะไม่ปรากฏในเอกสารบันทึกเนื้อหาการสนทนา เทปบันทึกเสียงการสัมภาษณ์จะถูกเก็บไว้ในตู้ที่ใส่กุญแจไว้ตลอดเวลา และจะทำการลบเสียงออกเมื่อการวิจัยสิ้นสุดลง สำหรับเอกสารบันทึกการสัมภาษณ์ ชื่อและที่อยู่ของคุณจะถูกแยกเก็บไว้ในตู้ที่ใส่กุญแจและดิฉันเพียงคนเดียวเท่านั้นที่จะสามารถใช้เอกสารเหล่านี้ ผลการวิจัยครั้งนี้จะถูกเสนอในลักษณะภาพรวมของกลุ่มและจะไม่มีข้อมูลใดๆที่บ่งชี้ถึงตัวบุคคล การสัมภาษณ์แต่ละครั้งดิฉันจะมอบเงินจำนวน 200 บาทแก่คุณเพื่อเป็นการตอบแทนสินน้ำใจที่คุณกรุณาสละเวลาในการให้ข้อมูลซึ่งเป็นประโยชน์ต่อการวิจัยครั้งนี้ แม้ว่า คุณจะตัดสินใจหยุดการสัมภาษณ์ หรือขอถอนตัวระหว่างการสัมภาษณ์ก็ตาม

ลายเซ็นของผู้วิจัย

วันที่

คำแถลงของผู้เข้าร่วมการวิจัย

ข้าพเจ้าได้รับคำอธิบายเกี่ยวกับการวิจัยดังกล่าวข้างต้นแล้ว ข้าพเจ้าสมัครใจที่จะเข้าร่วมการวิจัยครั้งนี้ ข้าพเจ้ามีโอกาสได้ซักถามข้อสงสัยต่างๆ ข้าพเจ้าเข้าใจดีว่าหากในภายหลังข้าพเจ้ามีข้อสงสัยเกี่ยวกับการวิจัยในครั้งนี้หรือเกี่ยวกับสิทธิของข้าพเจ้าในฐานะผู้เข้าร่วมการวิจัย ข้าพเจ้าจะได้รับคำชี้แจงจากผู้วิจัยที่มีชื่อปรากฏข้างต้น ข้าพเจ้านุญาตให้ผู้วิจัยใช้บันทึกทางการแพทย์ของข้าพเจ้าตามที่ได้กล่าวในใบยินยอมนี้และข้าพเจ้าได้รับสำเนาใบยินยอมนี้หนึ่งฉบับ

ลายเซ็นของผู้ร่วมการวิจัย

วันที่

สำเนา: ผู้ร่วมในการวิจัย

แฟ้มของผู้วิจัย

BIOGRAPHY

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