THAI WOMEN’S EXPERIENCES OF HIV/AIDS IN
THE RURAL NORTH:
A GROUNDED THEORY STUDY

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PLEASE NOTE

The greatest amount of care has been taken while scanning this thesis,

and the best possible result has been obtained.
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ABSTRACT

Thailand is a nation of some 60 million people, 2 million of whom are estimated to be HIV/AIDS infected and, of those who are infected, 80-90% were infected through heterosexual intercourse and, 10-20% are women. The Thai epidemic, which began in 1984, has been characterised as consisting in five “waves”. The first wave was spread through intravenous drug users (IVDUs); the second was spread through direct and indirect commercial sex workers (CSWs); in the third wave, spread was to the male clients of CSWs; in the fourth wave, to the wives of CSWs’ clients; and, in the fifth wave, to the children of infected women. The provinces of the upper north, which include Chiangmai, are considered to have the highest infection rates in Thailand.

The numbers of infected Thai women and children are considered to be increasing, the increase being attributable to the differential constructions of male and female status and sexuality in traditional Thai culture. These constructions are rooted in Theravada Buddhism, ancient mythology and folklore. Thai men are considered of higher status than Thai women and to be sexually insatiable. Thai women are expected to be extremely conservative in their sexuality. Consistent with the construction of male sexuality, Thai men are expected to engage in frequent pre and extramarital sex, with CSWs and/or casual girlfriends, as well as intra-marital sex with their wives. Thai women, in contrast, are expected to restrict their sexual activities to strictly monogamous, intra-marital relations. In addition, Thai men and CSWs are ambivalent with respect to condom use; many men prefer not to use them for commercial sex and their use in intra-marital sex is viewed as indicative of lack of trust. The lowly status of
Thai women militates against their objection to the risky sexual behaviours of their husbands and contributes to the increasing infection rate of women and children.

Thai culture constructs HIV/AIDS as an incurable, highly contagious and stigmatising disease; many of the problems faced by infected people, therefore, are a function of this negative cultural construction.

A vast amount of research has been undertaken world-wide to investigate multiple aspects of HIV/AIDS, and much has focused on Thailand. Despite the epidemiology of the fourth and fifth “wave”, however, no studies have been undertaken to date which focus particularly on the experiences of Thai women. In addition, and despite the high incidence of HIV/AIDS in the rural north, none have focused on the experiences of wives and widows in the rural north. This study is the first to do so.

Using grounded theory methodology, informed by the theory of social interactionism, this study examined the experiences of HIV/AIDS infected Thai wives and widows in the rural north. Specifically, it sought to answer two questions: (1) to explore the impact of HIV infection on married or widowed women diagnosed with HIV/AIDS in rural northern Thailand; and, (2) to understand how married or widowed women with HIV/AIDS in rural northern Thailand cope with HIV/AIDS.

Data were obtained from semi-structured interviews and participant observation of theoretically sampled HIV/AIDS infected Thai wives and widows in Chiangmai Province. A total of 24 participants were included in the study. Textual data were managed using Thai Ethnograph and analysed using constant comparative method.
Data collection and analysis proceeded concurrently using open coding and theoretical coding until saturation was achieved. This resulted in the development of a substantive theory explaining the experience of HIV/AIDS of participants.

The findings of the study revealed several problems with which participants were confronted and the processes they used to address them. Specifically, participants experienced the basic social problem of “Surviving With HIV/AIDS”. Properties and dimensions of “Surviving With HIV/AIDS” were found consistently in the data and this problem was identified as the core category. “Surviving With HIV/AIDS” was a function of four distinct but highly interactive and causally related groups of problems. These were identified as physical implications, psycho-emotional implications, economic implications and socio-cultural implications of HIV/AIDS. In order to deal with their basic social problem, participants utilised two distinct but complementary social processes; these were identified as “Hiding Out With HIV/AIDS” and “Hanging In With HIV/AIDS”. Hiding Out With HIV/AIDS entailed a range of strategies implemented to protect her husband, protect her children and protect herself from the actual or expected discriminatory behaviour of family and friends. These included telling lies, avoiding social contact and being clean and covered. “Hanging In With HIV/AIDS” was the process through which participants made the best of their predicament. It involved the highly active pursuit of a range of strategies to enable participants to live the best life possible, given their disease.

“Hanging In” began once participants had resolved to fight for their lives; it involved the active seeking of socio-emotional and financial support from a variety of sources. These included mothers and close family, government and NGO agencies and,
importantly, Persons With AIDS Group. In addition to actively seeking support, participants also adopted a healthy lifestyle, sought medical advice, took traditional herbal medicines and made merit. These strategies are largely consistent with those implemented by HIV/AIDS populations and for the same reasons; they are also consistent, but to a lesser extent, with those of people suffering from non-infectious stigmatising diseases and non-stigmatising chronic diseases.

Both “Hanging In” and “Hiding Out” were informed by a mixture of traditional Thai culture and ‘Westernised’ ideas. The findings of this study have implications for health policy more generally in Thailand and for nursing practice, education and research and these are discussed. It is suggested that any seriously therapeutic interventions and interventionist research studies must be congruent with traditional Thai culture.
Chapter One

Introduction to the Study and Overview of Thesis

Introduction

Sex, drugs, morality and death. These are the issues that elevate AIDS beyond the medical level of devastating illness to one encompassing sociologic, cultural, political and moral facets. Unlike other devastating and as yet incurable diseases such as cancer or Huntingdon’s Chorea, a diagnosis of AIDS often carries with it elements of disapproval, stigmatization, and discrimination. Not only is AIDS often considered to be a logical outcome of high-risk behaviours and, therefore, viewed as preventable, if not deserved, but the routes of transmission (sex and IV drug use) ignite the fears and anxiety of nations. A diagnosis of AIDS goes beyond the realm of posing a medical and personal crisis for the individual to a crisis of social, psychological, legal and financial proportions which may affect the patient’s entire world.


The tragedy that is Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS), and which is graphically reflected in the above quotation, affects, at a conservative estimate, over 30 million people world-wide (Way, Schwartlander & Piot, 1999). In Thailand alone, in the year 2000, the (Thai) Ministry of Public Health (MOPH), the World Health Organization (WHO) and several Thai Non-Government Organizations (NGOs) estimated that 2-4 million people would be infected, with 350,000-650,000 suffering from AIDS. Again, these estimates are likely to be conservative; under-reporting of HIV/AIDS is an international issue which makes the production of accurate incidence/prevalence statistics problematic.
The causal agent of HIV/AIDS was not identified until 1983 and the first case of HIV/AIDS was diagnosed in Thailand as recently as 1984. The first cases of HIV/AIDS were homosexual or bisexual men who, typically, were urban dwellers in the major Western democracies; spread was mainly through homosexual activities. HIV/AIDS infection in heterosexual people, including women, was virtually non-existent. Currently, however, 80-90% of HIV/AIDS cases are heterosexuals (who may or may not be intravenous drug users) and, in Thailand, 80-90% of these are men (Batterink, Roos, Wolffers, Intarajit & Karinchai, 1994); 10-20% of infected Thais, therefore, are women (Ruangjiratain & Kendall, 1998) and the number of infected women is considered to be increasing.

HIV/AIDS is a personal (individual) and global tragedy, not only because it is progressively debilitating and incurable, but also because it is preventable. The stabilizing and, indeed, the decreasing numbers of infected gay men in developed countries testifies to the positive, preventative effects of appropriate life-style changes. The extraordinarily low incidence of HIV/AIDS in urbanized commercial sex workers (CSWs) in the United Kingdom and mainland Europe also testifies to the positive effects of energetic and active prevention strategies.

HIV/AIDS is a personal and national tragedy, in Thailand, because traditional Thai culture militates against the implementation, particularly by women, of energetic and active preventative strategies. Gender roles, which are related primarily to Theravada Buddhism, folklore and ancient superstitions, and expressed through kreeng jai, (the hierarchy of social rules and protocols, which very tightly govern social life in Thailand) are particularly implicated in this respect (Bechtel & Apakupakul, 1999).
This chapter, therefore, will focus on an examination of relevant aspects of Buddhism, folklore and ancient superstitions as these affect gender constructions in Thailand. It will also briefly focus on the nature and importance of *kreng jai* in Thai culture. These discussions are central to an adequate understanding of the HIV/AIDS epidemic in Thailand. They will demonstrate clearly that the HIV/AIDS epidemic in Thailand is a function of the differential gender constructions of women and men. Culture is not merely the source of the HIV/AIDS problem in Thailand; by implication, it is also the source of the solutions to HIV/AIDS problems to which HIV/AIDS infected people have access.

The chapter will also provide a justification for the study and for the use of grounded theory methodology in it.

Firstly, however, in order to contextualise subsequent discussions relating to gender constructions and roles, a more general, if brief discussion of culture is required.

**Culture**

**Dietary**, linguistic, religious, historical, family, and social groups’ interactive and health-related behaviours are a function of cultural belief (Barnes, 1996). How an individual understands illness, disease, health and death, for instance, is learned through social enculturation and such understandings influence the behaviours an individual is willing to engage in to attain, retain or regain health. What counts as health and healthy behaviours is culturally constructed and can be learned and changed over time. Although there are common, even universal natural and social phenomena,
the meanings attributed to them and their consequent responses are group specific (Porter & Villarruel, 1993).

Culture affects the meanings of health and illness; it also conditions the uses and meanings of language. Language describes the boundaries and perspectives of a cultural system and reflects how social life is represented within that culture (Atkinson, 1992). People from different cultures use words, narratives and explanations differently according to culture-specific understandings. Language is also a perceptual filter; concepts acquire their meanings largely through their embeddedness in a culturally specific explanatory verbal network (Awa, 1979). In short, different cultures provide different interpretations of reality and its representation in thought.

**Grounded Theory and Culture**

Culture is the basis of constructions of health beliefs and behaviour; the researcher believes, therefore, that it must be considered from both the respondents' and researcher's perspectives in data collection, analysis and development of grounded theory. This viewpoint is not shared by Glaser (1978) who believes that variables such as race, gender, age and class must earn their way into a theory. Glaser's view seems mistaken. Firstly, the explanatory power of a Glaserian view of a grounded theory of rural Thai women's experiences of HIV/AIDS could be extremely limited for it could fail to attend to the cultural construction of HIV/AIDS for respondents depending on their linguistic and conceptual abilities. Secondly, a "grounded theory" which failed to take account of such cultural constructions would neither fit nor be relevant to the social realities of respondents (and both are characteristic of adequate grounded theories).
In addition, and inevitably, if a researcher is unfamiliar with the culture of her/his respondents s/he will automatically collect and analyze the data according to her/his own cultural bias. Similarly, how respondents frame their responses and conduct themselves in interviews in naturalistic settings is a function of their cultural habits, beliefs and learned style of interaction (Lipson, 1991). An understanding of such cultural learning, therefore, is clearly required to ensure accuracy of interpretation.

**Culture and This Study**

The researcher is Thai and was able, therefore, to be sensitive to appropriate research questions, interview techniques and insightful, generative questions (Barnes, 1996). In addition, the researcher, although Thai, is also reasonably fluent in English. This means that she possesses both two languages and the conceptual schemes in which they are embedded. This, in turn, allowed her to “translate” from one culture to another when linguistic equivalence was unavailable, that is, when strictly accurate translation was problematic due to language and conceptual differences. Moreover, Thai culture is not static; capitalism and increasing access to “Westernized” media have added a degree of modernity to traditional Thai culture (see below). Thus the clearly Western theoretical constructs of “Hanging In With HIV/AIDS” and “Hiding Out With HIV/AIDS” are not as inappropriate to Thai-derived data as they may first appear. Lastly, and in relation to this, the researcher was extremely diligent in the way she checked her (Western-influenced) analytic hypotheses with respondents throughout the duration of the study and undertook member checks of the substantive theory once it was developed.
Overview of Thailand

Thailand is a nation of approximately 60 million persons located in the central area of South East Asia and bordered to the west by Myanmar (Burma), to the north and east by Laos, to the southeast by Cambodia and to the south by Malaysia (Taywaditep, Coleman & Dumronggittigule, 1997). It is divided historically and culturally into four distinct regions: north, northeast, central plains and south which are further subdivided into seventy-six provinces. The capital, Bangkok, is situated in the central part. The population of Thailand consists of 86% Thai, 3% Chinese, 1.5% Malaysian, with the rest being people from other minorities such as hill tribes (Batterink et al, 1994). Thailand has a very young population with 45% of its people under 14 years of age, 49% between 15 and 59 years and only 6% over 60 years (Taywaditep, Coleman & Dumronggittigule, 1997). Thailand has grown rapidly in economic terms in the past two decades (Choowattanapakorn, 1999; Sittitrai, Phanuphak, Barny & Brown, 1992) resulting in a “Westernisation” of lifestyle, the rapid expansion of the tourist trade with a widespread sexual services industry. Approximately 20% of Thais live in urban areas, typically in nuclear families (Sittitrai et al, 1992); the remaining 80% of the population live in rural areas, typically in extended families (Havanon, Knodel & Bennett, 1992). Thais living in rural villages live more simple lives, rooted in rich traditions less influenced by capitalism and international cultures than urban Thais (Taywadipep, Coleman and Dumronggittigule, 1997). Both urban husbands and wives will often work at a distance from home whereas members of rural families will work in or in close proximity to their village. Rural families grow their own food, which consists mainly of rice. Formerly, married daughters and their husbands lived with the wife’s parents to help with housework and farming; currently, however, couples
establish their own households near the parental homes (Yoddumnern-Attig & Attig, 1993). In rural areas, where poverty is rife, girls have less opportunity than boys to continue their education beyond four years (Whittaker, 2000); boys who are poor can escape their poverty by becoming monks and studying concurrently.

Each region in Thailand exhibits distinctive variations in subcultures; however, the country is unified by its devotion to both the monarchy and to Buddhism (Sittitrai et al, 1992).

**Buddhism and Thai People**

The national religion of Thais is Theravada Buddhism (Chandra-ngarm, 1999; Mulder, 1990) and 95% of Thais consider themselves Buddhist (Batterink et al, 1994; Chadchaidee, 1994; Komin, 1990). Buddhism is deeply rooted in the minds of Thais and has been a significant part of their cultural background for many centuries (Chadchaidee, 1994). It teaches people to live in the spirit of Metta and Karuna, that is, kindness and compassion (Suriyabongs, 1958). However, Buddhist ideology also represents women as inferior to men and negatively values female sexuality; Buddhism, therefore, is the basis of the exploitation and subordination of women in Thailand (Thitsa, 1983).

The most obvious Buddhist-derived sexual differentiation in Thai villages is centered around religious activities at the temple where male ritual authority and superior religious status is reinforced.
Women cannot be ordained (see below); men perform all the public roles of Buddhism, as ordained monks or as lay officiates, leading the chanting, conducting rituals and as members of the wat (temple) committee. In addition, the organization of space in the meeting hall clearly denotes the differential moral status distinctions between monks and lay persons, elders and younger people and the divisions between women and men. Monks sit upon a raised platform, denoting their higher status. Elderly men sit closest to the monks, followed by younger men. Women, who usually outnumber the men attending, sit around the perimeter. The elderly men make merit (see below) by placing food in the monks’ bowls first, followed again by the younger men. Not until the youngest boy has made his offering will the most elderly woman lead the other women to make their offerings (Whittaker, 2000).

In addition, of the 227 monastic rules of Buddhism, one demands celibacy and another prohibits any physical contact with women. Women, including the monks’ family members, are precluded from certain activities in religious ceremonies to avoid the possibility of ritual purity violation (Taywandtep, Coleman & Dumronggittigule, 1997).

Belief in The Law of Karma

Buddhists believe that their lives are in a chain of rebirth where they are continuously reborn in human or animal form, in either gender, depending on deeds or karma of the previous life (Choowattanapakorn, 1999; Ratanakul, 1996). “What we are now is the result of what we were and have been before” (Ratanakul, 1996 p. 31). As the proverb says, “do good, receive good; do evil, receive evil”. Karma is the law of moral causation (Piyadassi Thera, 1989; Bodhi, 1991); it basically relates to will, a force to
action (Bodhi, 1991). The present life is not entirely the result of previous lives, however; the present form of existence can be changed or redeemed by current deeds. The present life can thus be affected by a person’s conduct in it (Heitman, 1992; Kirsch, 1975).

To Thai Buddhists the world seems to be imperfect and imbalanced. Among human beings, some are seen to be born into misery while others are born into a state of abundance. The imbalance is due to individuals’ *karma* of previous lives (Gorkom, 1988). For instance, HIV-infected persons may believe that their infection is their punishment for bad behaviour in a previous life.

Thus the law of *Karma* assists an individual to understand her/his own health. Good health is the correlate of good *karma* in the past and vice versa (Ratanakul, 1996). Each person’s *karma* is a mystery as no one knows their own *karma*. If someone has an illness with a *karmic* cause, it will not be cured until the *karmic* debt is repaid (Ratanakul, 1996). Belief in *karma* also enables people to cope more easily with the painful reality of life, for instance, the suffering associated with HIV infection.

Buddhism teaches people with incurable diseases to be patient and accept their own *karma* (Ratanakul, 1996; Whittaker, 2000). Performing good deeds, however, affects one’s own *karma* and one may make merit by practising morality (*sila*), mental discipline (*samadhi*) and wisdom (*panna*) (Ratanakul, 1996).
Merit-Making

Merit-making, "Thumbun", is generally performed for the present and a better next life; merit-making consists in helping others, sharing merit with them, providing sons for the priesthood, and promoting and distributing the Buddhist teaching (Mulder, 1990). One’s karma is influenced positively by thumbun (Pramualratana, 1992; Songwathana, 1998) and thus it is a vital part of villagers’ life (Phongphit & Hewison, 1990). Most Buddhists believe that by supporting the temple and the monks by donations of food, money or sponsoring temple ceremonies, they will gather merit (Songwathana, 1998). They also know that gathering merit in this way is relatively simple; the temple “wat” is the focal centre of the village, particularly during festivals (Kirsch, 1996; Office of the Prime Minister, 1991). Villagers typically make merit every Buddhist holy day, “Wan Phra”, (four times a month according to the lunar calendar) by going to the wat in order to offer food, listen to monks’ sermons and practice meditation (Chan-ngarm, 1999; Phongphit & Hewison, 1990).

Meditation

Meditation is considered able to ease suffering by gradually obtaining a better understanding of the reality and meaning of life. Meditation in Buddhism aims to improve the mind, that is, it trains the feelings, qualities and habits of the mind to be virtuous and skilful (Payutto, 1993). Meditators make tremendous efforts to understand precisely the nature of the psycho-physical phenomena taking place in their own bodies (Amawattana, 1993). Meditation takes effort and patience; the specific term for patience in Buddhism is Khanti (Amawattana, 1993). Meditation heightens people’s consciousness, Samadhi, the correct practice of which maintains the mind and the mental properties in a state of balance (Piyadassi, 1989).
Traditional Thai Culture and Modernity

Capitalism, western biomedicine and access to 'Western' ideas, which are "beamed" daily into Thai homes, have begun to influence Thai culture.

In terms of capitalism, the advent of waged labour has disadvantaged women politically. Firstly, the tasks, which traditionally have been undertaken by men, attract higher wages; the role of men as primary bread winners and the dependence of women upon men for financial security has, therefore, been reinforced. Secondly, income from agricultural production in villages is increasingly insufficient to meet family needs; this results in large numbers of young women and men migrating, at least seasonally, to major cities to find work. Migration separates women from their traditional sources of status (wife and mother; see below). Education and wealth have become the predominant status markers for urban Thais, both male and female (Muecke, 1984). However, since men typically receive more education and higher wages than women, women's inferiority is again reinforced.

In terms of biomedicine, although it has become the dominant desired form of therapy for HIV/AIDS, (for those who can afford it), it has not replaced traditional non-biomedical healing therapies. This is despite biomedicine and traditional healing being based upon quite different understandings of the body. (Thais view the person not as an entity separate from the community but rather as a process of embodiment of spirits and flesh, karma and community). These differences are transcended every day as people infected with HIV/AIDS seek care and healing from various practitioners (Whittaker, 2000).
A number of other 'Western' innovations and behaviours have been incorporated into Thai culture, but some only insofar as they are commensurate with it. For example, the chivalrous manners of Western men toward women (e.g. opening doors) have been incorporated easily because they fit with traditional Thai views of women being noble but weak(er). Feminism, in contrast, has not been incorporated because feminist manifestos are antithetical to Thai gender constructions (Taywaditep, Coleman & Dumronggitigule, 1997). This is particularly true in rural communities; however, elements of Western feminism have been adopted by young urban Thais, including women.

Increasing numbers of unmarried young urban Thais are cohabiting in stable relationships; they are enabled to do this because of the anonymity afforded by "big cities" and because of the availability of contraceptives (Nelson, Celentano, Eiumtrakul, Hoover, Beyrer, Suprasert et al, 1996). As might be expected, however, this behaviour is disparaged by Thais in rural areas. These sexually active young women are known as ying ruk sanuk, fun-loving women or kai long, stray chicken (Taywaditep, Coleman & Dumronggitigule, 1997).

**Gender and Sexuality in Thailand**

Thailand is a male-dominated, patriarchal society with political and corporate leadership being in the hands of men (Ruanghaiatain & Kendall, 1998; Taywaditep, Coleman & Dumronggitigule, 1997); nevertheless, Thai women, especially rural women, find power in the home in their role as mother-nurturer (Keyes, 1984). The mother nurturer "mae" role is idealized in the female code of social and sexual
conduct to the extent that a woman is not considered fully adult until the birth of her first child (Tatwaditep, Coleman & Dumronggittigule, 1997). In addition, little girls and adolescent women are nicknamed “mae” in their households in preparation for their “adult” status.

The Ideal Thai Woman

Traditional Thai culture defines a virtuous woman (kulasatrii) as proficient and sophisticated in household duties; graceful, pleasant yet unassuming in appearance and social manners; and conservative in her sexuality (Sittitrai & Brown, 1994; Taywaditep, Coleman & Dumronggittigule, 1997). Curiosity about sex is considered highly inappropriate before marriage (Ford & Kittisuksthathit, 1994) and premarital sex is forbidden. Thai women are expected to be virgins at marriage and remain strictly monogamous with their husbands (Cash, Anasuchatkul & Busayawong, 1995). The traditional kulasatrii is supportive and cooperative at home and defers in all things to her husband (Taywaditep, Coleman & Dumronggittigule, 1997). Indeed, during courtship, “good” young women practice deference and submission to their future potential husbands. The kulasatrii is the female gender ideal to which all Thai women aspire; it is an ideal which is expressed in traditional Thai drama and folklore and reinforced in contemporary literature, radio and television (Taywaditep, Coleman & Dumronggittigule, 1997).

This cultural construction of the kulasatrii is derived from a combination of Buddhist beliefs, as outlined above, folklore myths and ancient superstitions and “Western” radio and television influences.
To begin with, folklore myths and ancient superstitions centered on symbolic female pollution where certain female body parts, and their ‘products’, were seen as polluting and harmful to men. These parts and products included genitalia, buttocks and menstrual blood and anything which came into contact with them was also considered harmful. In addition, because female ‘parts’ and ‘products’ were pollutant (inferior), men had to keep themselves physically above (superior to) them.

Remnants of these myths and superstitions still persist in Thai culture where fatalism (duang) remains very powerful. Thai men, even today, avoid walking under washing lines containing women’s undergarments and skirts and they do not have intercourse with menstruating women or engage in cunnilingus. They believe their karma will be jeopardized if they do.

Moreover, Thai folklore, music and ‘popular’ literature and media presentations idealize romantic love between men and women. A distinction between love (khuaam ruk) and lust (khuaam kraï) is impressed on young people to deter them from premarital sex. The prohibition on premarital and extramarital sex is based in the Third Buddhist Precept, that is, to refrain from any sexual activity that might cause sorrow, and Western medical and sexual-psychological theories (Taywaditep, Coleman & Dumronggittigule, 1997). The Third Precept is used to teach young people (and to remind older people of) the dangers of lust. These prohibitions serve to protect the importance of lineage in Thai culture.

The ideal of the kulasatrii is also based in Buddhism’s construction of women’s inferiority and the belief in karma; only men may be ordained as monks, which is the
ultimate redemptive act. The redemption of the good woman, therefore, is a function of the actions of the men in her life.

Reincarnation is a central tenet of Theravada Buddhism where the quality of the next life (in terms of species, gender and advantage) is a function of the merit acquired in previous lives i.e. karma (see above); as already noted, however, women are excluded from the ultimate merit-making act, that is, ordination as a monk. A kulasaatrii, therefore, must make merit by enabling the ordination of the men in her family. She “gives” her sons to the monkhood, at least temporarily (see below) and nurtures religious pursuit through alms giving (Keyes, 1984).

It is expected that all young men upon reaching the age of 20 years will enter the monkhood for 3 months during the Buddhist Lenten period. This temporary ordination is seen as a rite of passage from raw or immature man to ripe or wise man (Taywaditep, Coleman & Dumronggittigule, 1997). The merit acquired through this temporary ordination is transferred to a man’s wife upon his marriage.

The kulasaatrii, because she cannot be ordained, must strive to avoid accumulating demerit and this includes premarital and extramarital sex. In addition, because she recognizes that her strongest merit lies in the ordination of her sons, she feels pressured to marry and have children. This pressure is expressed in behaviours which are likely to increase her likelihood of marriage (i.e. submissiveness, deference, sexual conservativeness, etc).
In Thai households the men are the primary income earners and are generally in charge of the household’s finances. Women are expected, however, to manage the finances on a day-to-day basis (Batterink et al, 1994: Sittitrai et al, 1992).

In addition, Thai women are expected to undertake all household duties; the good woman “gets up before her husband and goes to bed after him” (Taywaditep, Coleman & Dumronggittigule, 1997). Even when a Thai wife has employment outside the home, it is still expected that she will fulfil all her household “duties” (Taywaditep, Coleman & Dumronggittigule, 1997). If she is not employed outside the home, the good Thai wife will engage in vegetable growing, sewing, craft etc. and, by selling such products, she will contribute to the family’s income (Wawer, Podhisita, Kanungsukkasem, Pramualratana & McNamara, 1996).

Both sons and daughters are valued in Thai families. Sons are valued because of their potential ordination and merit-making abilities for parents; daughters are valued because they are reliable and dependable and are expected to care for parents in their old age (Pyne, 1994).

In terms of family dynamics, women maintain strong connections with their mothers even when migration and poverty make contact difficult (Whittaker, 2000). Women who work in cities will often send money home to their families, to make merit, which is known as bunkhun (see below), they will also visit them regularly and most return to their villages when financial targets have been achieved or when their employment or marriage terminates (Pyne, 1994).
The Ideal Thai Man

The image of the ideal Thai man is quite different from that of the ideal woman. To begin with, there are two ideal images available to Thai men. The first, which is denied women on gender grounds, is the monastic-recluse image (following Buddha) or ordination into the Songha. During periods of ordination, which are always available options for men, worldly attachments and sexuality are eschewed. The second image, however, is the embodiment of masculinity found in other cultures, that is, authority, courage, self assurance, physical and emotional strength and sexual prowess (chaaii chaatrii). The masculine attributes of the chaaii chaatrii find expression, typically, in the behaviours of a nug layng which, when translated into English, means a cross between a playboy and a gangster (Taywaditep, Coleman & Dumronggittigule, 1997).

The nug layng is a man of action who works hard and plays hard, is loyal to friends, fierce to foes and also a great womanizer (Taywaditep, Coleman & Dumronggittigule, 1997). This secular ideal male image has evolved over the years to become the antithesis of the monastic-recluse ideal. Manliness is now explicitly associated with what traditional Thai culture construes as vices: smoking, drinking, gambling, womanizing, commercial sex, minor wives, public brawls, etc. Thai men who prefer not to participate in these activities are disparaged by other men as kathoeys (not a genuine man) or naa tua mia (“the female face”).

Traditional Thai culture views the male sexual appetite as insatiable (Ruangjiratain & Kendall, 1998; Taywaditep, Coleman & Dumronggittigule, 1997), which requires a range of outlets to protect “nice” women from rape (Dumronggittigule, Sombathmai,
Taywditep & Mandel, 1995). (This view is, of course, shared by Thai women; see Viravaidya et al, 1994.) Young men speak openly about sex and construe intercourse as a forceful act or an act which satisfies their greed (Chompootaweep, Yamarat, Poomsuwan & Dusitsin, 1991). They are expected to buy sex from CSWs because it is not available from women aspiring to be kulasatrii.

A Thai man after the age of fifteen who does not visit CSWs is not considered a man (Ungsongtham Hata, 1995) and he will be accused of being homosexual (Gray, 1991); indeed, he will probably be introduced to commercial sex by his father as part of his “growing up”. Visiting prostitutes is a socially and culturally accepted form of behaviour for a very substantial proportion of the Thai male population (O'Reilly, Islam & Sittitrai, 1999), usually preceded by an all-male evening of dining and drinking (Brummelhuis, 1993; Ungsongtham Hata, 1995). Most Thai males have visited CSWs at least once in their life and their first sexual intercourse experience is usually with CSWs (Beyrer, 1995; Havanon, Knodel & Bennett, 1992). In addition, Thai males feel there is no stigma attached to the frequenting of prostitutes because, as suggested above, it is seen as an indication of their virility (Gray, 1991). About 70 to 80% of all Thai males have experience with prostitutes (Brummelhuis, 1993; Gray, 1991), and about 30-40% use their services more or less regularly (Brummelhuis, 1993).

Two studies exemplify Thai attitudes to CSWs and men. The first, by Kitsiripornchai, Ungchusak, Markowitz, Mason and Leucha (1996), found that 39% of married men had sex with CSWs and 42% with casual girlfriends. The second, a study by Viravaidya, Obremkey, Lamsam, Sittitrai, Limprasitrong and Jittangkul (1994),
revealed that female informants felt that it was better for a man to buy sex from a CSW than to seduce a “nice” girl.

In addition, it was traditionally socially acceptable in the past for a Northern Thai man to have multiple or “minor” wives. Currently, however, the emphasis is on monogamous marriages (Beyrer, 1995); it has become socially unacceptable for Thai men to have minor wives. This is due to the fear in Thai families that the addition of minor wives to the family will cause social disruption and bring additional financial strain. This fear has led to women preferring their husbands to visit prostitutes rather than to take a minor wife (Lyttleton, 1994; Sittriraksa, 1992). The visiting of brothels, therefore, has become an accepted or normal practice (Ungsongtham Hata, 1995).

Interestingly, both husbands and wives typically believe that the husband’s use of CSWs helps to preserve their marriage. Women complain that their household duties are such that they are too tired for sex; in addition, pregnancy is normally accompanied by sexual abstinence (to protect the fetus). In contrast, husbands complain that their wives are sexually unresponsive and lack physical attractiveness. The use of CSWs, therefore, is seen by both partners to provide a sexual outlet for the husband which does not threaten the stability of the marriage (Taywaditep, Colemen & Dumronggittigule, 1997). This is despite an HIV/AIDS seropositivity of 65% in CSWs and a recognized ambivalence to condom use on the parts of both CSWs based in the rural north (Celentano, 1994) and their clients (see below). CSWs are recognized to be a hugely important source of HIV/AIDS infection in Thailand.
It is the Thai male’s demand which continues to ensure the availability of extramarital sex outside of traditional relationships with women (Ungsongtham Hata, 1995) and even though most women would prefer their husbands not to visit prostitutes, they passively accept this behaviour (Viraviadya et al, 1994), as indicated previously. In addition, Thai culture forbids women to talk openly to husbands about extra-marital sex or to influence them to use condoms. The kulasatrii is expected to trust and believe in her partner’s honesty and fidelity even when she has evidence to the contrary (Ruangjiriratna & Kendall, 1998). Those women who (infrequently) attempt to introduce condoms into their marital relationship are often perceived as not trusting their husbands and, indeed, may even be perceived as unfaithful themselves.

Refusal to have sex, even when it is recognized as ‘risky’, leads to marital conflict and divorce. Divorce is stigmatizing for women in Thailand (women are not ‘allowed’ to have separate lives) and results in women’s loss of economic security (Ruangjiriratna & Kendall, 1998).

Life for the kulasatrii is to accept, without question, a strict patriarchal social structure and perceive that way of life as right and moral. Because of this, the kulasatrii has no power over her own body and life and no control over her sexual health and decision-making.

The kulasatrii learns and earns her place in Thai society through learning and exercising kreng jai.
**Kreng jai**

As noted earlier, p 12, *kreng jai* refers to the very tight network of social rules and protocols which underpin gender (and other) roles. Learning *kreng jai* is a central component of Thai socialization.

*Kreng jai* is the means whereby Thais maintain social harmony and conformance and avoid conflict; it is the means whereby community and spiritual harmony become the accepted way of life (Bechtel & Apakupakul, 1999). It is, as the previous discussion demonstrates, both hierarchical and patriarchal but it also provides an important mechanism for social support.

The maintenance of family and community harmony and spiritual well-being is the central motivation of *kreng jai*; its deconstruction, therefore, which can result from HIV/AIDS infection, creates chaos and distrust among individuals and families. It has even been suggested (Bechtel & Apakupakul, 1999) that the re-establishment of *kreng jai* (and the social harmony and spiritual well-being it ensures) is the most important psychosocial task which HIV/AIDS infected Thais face.

**The Research Method**

The choice of research method relates to the nature of the research questions. The subjective nature of the impact of HIV/AIDS on individual women’s lives rendered it appropriate to use a qualitative method to investigate the ways and the conditions in which married or widowed Thai women perceive and experience HIV/AIDS. Qualitative methods, which focus on context-dependent meaning and understanding,
can assist researchers to add to our understanding of the nature and dimensions of the subjective experience of HIV/AIDS (cf. Walker, 1996).

Grounded theory was the qualitative method of choice in this study. Firstly, it investigated a substantive area that has not been investigated previously (Bowers, 1988; Burns & Grove, 1993; Strauss & Corbin, 1990). Secondly, it aimed to contribute to nursing’s body of HIV/AIDS related knowledge by developing (an inductively derived) theory, which is grounded in and ‘true’ to the data. Thus it aimed to provide a description and explanation of the substantive phenomenon of HIV/AIDS for married and widowed women in rural, northern Thailand which, if sufficiently developed, would enable prediction and appropriate preventative and/or therapeutic prescription.

**Justification for the Study**

It has been noted above that 10-20% of HIV/AIDS infected people in Thailand are women. This percentage has increased from 0% in just 16 years and is believed to be continually increasing. It has also been demonstrated in the preceding pages that this increasing incidence is due largely to differential gender constructions in Thailand. Unprotected sex with CSWs followed by unprotected sex with wives remains the most common route of infection.

Many studies have been undertaken, from 1986, to examine aspects of the Thai HIV/AIDS epidemic. These, however, have tended to focus on 1) risk behaviours and sexual risk behaviour associated with HIV/AIDS; 2) health-seeking behaviours and coping processes of persons with AIDS (PWAs); 3) the societal reaction to PWAs; 4)
the role of families, communities, and Non Government Organizations (NGOs) in dealing with AIDS: 5) the economic, social and psychological impact of AIDS on PWAs; and 6) national policy on ethical issues surrounding treatment of PWAs and the support of their rights (Boonmongkon, Pradapmook & Reaungsorn, 1998). In addition, most of the research has been quantitative in nature; even the small number of studies on illness behaviour and coping processes of PWAs has tended to be quantitative (Sangchart, 1998). Such studies have produced useful information, especially in terms of policy development; however, they have not sought to explore the totality of the HIV/AIDS experience, that is, the issues and problems confronted by specific groups of people and how they cope with these.

There have been exceptions to this quantitative tendency in Thai HIV/AIDS related research. The Bechtel and Apakupakul (1999) study of kreueng jai and HIV/AIDS in southern Thailand used narrative method and another study by Ruangjiritain and Kendall (1998) used a critical hermeneutic approach to study Thai women’s risk of infection.

The Ruangjiritain and Kendall study is exceptional for a second reason; it focuses on women with HIV/AIDS. Giffin (1998) and Powell (1992) both point out that for a decade HIV/AIDS research has tended to focus on men; women and their particular concerns have been largely ignored.

This study is justified, therefore, because it focuses on the experiences of married or widowed Thai women with HIV/AIDS in the rural north; it is the first study undertaken with this group of people. The setting of the study, Chiangmai, is also
justified; Chiangmai, together with Chiangrai, Lumpoon and Payao are considered to have the highest rate of infection in the country.

In addition, and on a more personal note, the researcher has observed that married rural Thai women with HIV/AIDS appear to remain relatively healthy for 3-5 years longer than their husbands. She observed this whilst a member of the committee evaluating Care International/Thailand’s Living with Aids Project, between 1993 and 1995. The researcher thought this was interesting. For even though they were infected, Thai women still fulfilled, or attempted to fulfil, the full range of kulasatrii responsibilities. This was despite the fact that these married/widowed women knew that they could only have been infected by their husbands. The researcher wondered what problems this presented for these women and how they managed them.

Women, as care providers themselves, represent a special challenge to nurses caring for people with HIV/AIDS. The task of nursing is to assist the person living with HIV/AIDS to maintain her or his quality of life, however they wish to define it. This entails learning what the person defines as problematic in their lives and what strategies are acceptable and effective in their control and/or amelioration. Until this has been accomplished, it will not be possible for nurses to provide effective, culturally acceptable care to individual people with HIV/AIDS or to contribute meaningfully to the development of sensitive and effective HIV/AIDS health policy. This study aimed to do this.
Aims of This Study

1. To explore the impact of HIV infection on married or widowed women diagnosed with HIV/AIDS in rural northern Thailand.

2. To understand how married or widowed women with HIV/AIDS in rural northern Thailand cope with HIV/AIDS.

Summary and Thesis Plan

Summary: Chapter One

Thailand has a population of 60 million people with only 6% of them being over the age of 60 years. It is estimated that 2-4 million Thais are infected with HIV and that 350,000-650,000 are suffering from AIDS. HIV/AIDS is now the number one killer of people between 25-44 years in Thailand.

The first case of AIDS in Thailand was diagnosed in a homosexual man as recently as 1984; currently 80-90% of infections are due to heterosexual transmission and 10-20% of infected Thais are women. The number of infected Thai women is considered to be increasing, despite HIV/AIDS being preventable through appropriate lifestyle changes and the use of condoms.

Gender roles, which are related to Theravada Buddhism, folklore and ancient superstitions and expressed through kreueng jai, the social rules which govern Thai society, militate against Thai women implementing appropriate preventative strategies. The ideal Thai woman, the kulasatrii, defers in all thing to her husband; she is submissive, obedient, a virgin on marriage and strictly monogamous thereafter. The ideal Thai man, the chaaii chaatrii, however, drinks, brawls and is sexually insatiable.
He begins to frequent CSWs in his mid-teens and continues to do so even after his marriage. Both he and his wife consider such behaviour normal.

Thai wives, husbands and CSWs remain ambivalent with respect to condoms. Condom use is seen as appropriate only for casual, extra-marital sex; condom use in intra-marital sex is considered reflective of lack of trust. The kulasatrii acts at all times as though she trusts her husband even when she has evidence that he is not trustworthy.

Approximately 65 % of CSWs in Chiangmai are HIV positive; men who have unprotected sex with them become infected and subsequently infect their wives during unprotected sex. CSWs remain an important source of HIV infection in Thailand and the epidemic will continue, with increasing numbers of women (and children, see Chapter Two) becoming infected as long as unprotected sex is culturally acceptable in Thailand.

This study is the first to investigate the meanings of HIV/AIDS in the lives of married and widowed Thai women. It investigated the effects of HIV/AIDS infection, both physical and psychosocial, on these women’s lives and how they managed them.

It was conducted in the rural north, in Chiangmai Province, which has one of the highest HIV/AIDS infection rates in Thailand.
Thesis Plan

Chapter Two focuses on the cause of HIV/AIDS and the transmission routes of HIV-1 and HIV-2 and their epidemiological importance in developed and developing countries. It also focuses on the incidence and epidemiology of HIV/AIDS in northern Thailand and highlights the role of CSWs and (lack of) condom use in disease transmission.

Chapter Three focuses on the clinical and psychosocial manifestations and implications of HIV/AIDS in relation to HIV/AIDS infected people, in general, and in relation to infected Thai women, in particular. It also focuses on the psychosocial tasks which HIV/AIDS infected people must address to manage their disease and the factors, which assist them to do this.

Chapter Four provides a comprehensive discussion of grounded theory method. This includes a review of the different procedural recommendations of the method’s leading theorists, and their rationales. Symbolic interactionism, grounded theory’s generative theoretical framework is also discussed and its connections to grounded theory method are made explicit. The relevance of grounded theory to this study is also made explicit. It also provides details of how grounded theory methodology was applied in this study. Precise details of what the researcher did, in terms of data collection and analysis are provided to ensure an adequate audit trail.

Chapter Five focuses on the basic social problem with study participants had to contend; this was “Surviving With HIV/AIDS” in rural, northern Thailand. Many of the problems, which “Surviving With HIV/AIDS” subsumes, are either directly or
indirectly attributable to the socio-cultural constructions of HIV/AIDS in northern Thailand.

Chapter Six focuses on the two, complementary social processes which study participants' used for “Surviving With HIV/AIDS”. These were “Hanging In With HIV/AIDS” and “Hiding Out With HIV/AIDS”. These two processes enabled participants to come to terms with the fact that they had an incurable disease and make the best of their predicament. They also enabled the women to shield themselves and those close to them from the social discrimination which normally accompanies the disease.

Chapter Seven, the closing chapter, discusses the findings in the context of contemporary literature. Additionally, it discusses the implications of the findings for nursing practice, research and education and for health service policy more generally. The limitations of the study are also addressed.
Chapter Two

HIV/AIDS: Cause, Transmission and Epidemiology

Introduction

This chapter focuses on three important elements of the HIV/AIDS phenomenon. Firstly, it focuses on the cause of Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS). The history of the discovery of HIV/AIDS explains why it was initially considered to be a disease limited to gay and bisexual men. This discussion will also include a description of the life cycle of retroviruses and distinguish between HIV-1 and HIV-2. The zoonotic origin of HIV-2 will be noted. Secondly, the chapter will discuss the transmission routes of HIV-1 and HIV-2 and their epidemiological importance in developed and developing countries. It will be shown that heterosexual transmission is currently increasing in incidence worldwide and is the commonest route of transmission in developing countries. The factors likely to influence the chances of infection, including unprotected sex, especially anal sex, the presence of other sexually transmitted diseases (STDs) and the relevant anatomical details of the female and male genitalia will be outlined. Finally, the chapter will focus on the incidence and epidemiology of HIV/AIDS in northern Thailand, highlighting the role of CSWs and condom use in disease transmission.

The Cause of HIV/AIDS

Acquired Immune Deficiency Syndrome (AIDS) is a disease caused by a virus which is known as HTLV-III or Human T-cell Lymphotropic virus type III, LAV or Lymphadenopathy Associated Virus and ARV or AIDS-associated Retrovirus (Cunningham, 1994; Flaskerud, 1989; Hubley, 1995; Pratt, 1991). The disease was
not recognized until 1981 when three homosexual men who all presented with Kaposi’s sarcoma and pneumocystis carinii pneumonia (PCP) were discovered to be severely immunosuppressed (Peters, 1996). Pratt (1991) states that, “In May 1986, a subcommittee of the International Committee on the Taxonomy of Viruses proposed that AIDS retroviruses be officially designated as the ‘human immunodeficiency viruses’ (HIV)” (p.8). The first type of this virus is now named Human Immunodeficiency Virus Type 1 (HIV-1), which was discovered in France by Montagnier and colleagues in 1983 from a patient with LAV (Cunningham, 1994; Cunningham, Dwyer, Mills & Montagnier, 1997; Flaskerud, 1995). In 1985, a second virus, HIV-2, was discovered in West Africa (Ancelle-Park & De Vincenzi, 1993; Hubley, 1995; McClure, 1992; Way, Schwartlander & Piot, 1999). HIV-2 causes almost the same disease as HIV-1 but is sufficiently different from HIV-1 serologically and molecularly to be considered separate i.e. its latency period is longer than HIV-1 and vertical transmission from mother to neonate is rare (McClure, 1992). If epidemiological risk factors for HIV-2 infection are present, it is recommended to test for both HIV-1 and HIV-2 (Coombs, 1999).

Both HIV-1 and HIV-2 are thought to have originated in non-human primates although the evidence supporting the cross-species (zoonotic) transmission of HIV-2 is by far the stronger (Swanstom & Wehbie, 1999). The initial range of HIV-2 was confined to West Africa and overlapped with the range of one indigenous non-human primate, the sooty mangabey (Cerocebus atys). In addition, and as indicated above, HIV-2 grows less well in humans, giving lower viral loads and slower disease progression.
HIV-1 and HIV-2 belong to one of seven distinct retrovirus genera, the lentiviruses, so
called because they establish chronic infections that result in long incubation periods
followed by chronic symptomatic disease (lenti = slow, Latin). The term “retrovirus”
refers to a diverse family of enveloped, single-stranded ribonucleic acid (RNA) viruses
whose replication and expression are dependent upon the integration of a double-
stranded deoxyribonucleic acid (DNA) intermediate form (provirus) into the host cell
genome (Coffin, 1992; Temin, 1992).

All retroviruses, including HIV-1 and HIV-2, produce reverse transcriptase (RT)
which was discovered in retrovirus particles in 1970. RT allows the transcription of
the viral genome into the DNA of the host cell (Swanstrom & Wehbie, 1999). RT is
associated with the viral nucleocapsid core, which is cone shaped in HIV-1 and HIV-2
(Swanstrom & Wehbie, 1999).

The HIV-1 group of viruses cluster into distinct lineages that are classified as subtypes.
Infections in Western Europe and the United States of America (USA) are due almost
exclusively to subtype B whereas infections in Thailand are due to subtypes B and E.
Subtype B is spread through intravenous drug users (I.V.D.Us) and Subtype E is
spread through heterosexual contact, especially that involving commercial sex workers
(Swanstrom & Wehbie, 1999).

**Retrovirus Life Cycle**

The life cycle of retroviruses is similar to that of all viruses: binding onto host cell
surface; entry into host cell; replication and expression of the viral genome; virus
assembly; exit from host cell.
HIV-1 and HIV-2 bind onto the host cell surface specific receptor, the CD4 molecule, via the so-called envelope glycoprotein “Env” which is present on the surface of the viral particle. The CD4 molecule is a glycoprotein found predominantly on the surface of a subset of T lymphocytes (T helper cells) and on the surface of macrophages, some monocytes, glial cells and gastro-intestinal cells (Green-Nigro, 1999) which may be other targets of replicating virus in the body. Mature CD4+ T cells are the major source of lymphokines, which provide inductive signals for the activation and regulation of multiple limbs of the host immune response. Macrophages are cells that ingest proteins, including those derived from foreign pathogens, and process and present them in such a way that they can be recognized by antigen-specific T-lymphocytes. There is interaction between CD4 molecules on T-helper cells and the major histocompatibility complex (MHC; also known as human leucocyte antigens, HLA) class II molecules expressed on the surface of antigen-presenting cells for the efficient recognition of foreign antigens by T-helper cells and their consequent mobilization to facilitate cellular and humoral immune responses (Feinberg, 1997).

The role of CD4 when expressed on the surface of macrophages is less clear, but the molecule is found on many of the macrophages and related cells (see above). However, the physically intimate interaction between macrophages and CD4+ T cells which underlies the process of antigen presentation and recognition provides an efficient means of virus transmission between interacting cells. In addition, because macrophages are present in tissues throughout the body and appear to be more resistant to the cytopathic consequences of HIV infection, they are believed to represent significant vehicles for dissemination of HIV during the initial infection. They are also
thought to provide important reservoirs for the virus throughout the cause of HIV disease (Feinberg, 1997).

Cell surface expression of CD4 is necessary to permit productive infection of T-lymphocytes, but it is not sufficient. HIV can enter resting T cells but efficient progression through the virus replication cycle will not occur unless the host cells are activated and proliferating. This is because RT is inefficient in resting T cells.

The HIV-1 replication cycle begins when the retrovirus particle binds, via its Env glycoproteins, to the CD4 receptors that protrude from the host cell surface (Cullen, 1993). The binding of virus to host cell results in the fusion of the two cell membranes, which allows the viral nucleocapsid to enter the target cell.

The events, which result in membrane fusion, are not yet clear; it appears, however, that Env binding to CD4 alone is not sufficient. One or more additional cellular cofactors are required. CXCR-4 (fusin, LESTR), a heterotrimeric G protein-coupled receptor, is currently considered as one of a range of potential co-receptors for entry and infection with T-cell tropic strains of HIV (Koenig & Fauci, 1999).

Reverse transcriptase, which was packaged during virion formation, mediates the synthesis of viral DNA in the next round of replication. DNA synthesis takes place in the cytoplasm of the host cell.

Within partially disassembled viral core complexes (i.e. nucleoprotein complexes) reverse transcriptase first catalyses the synthesis of a viral DNA strand from the viral
RNA. The enzyme RNase H then degrades the original viral RNA and the RT completes the synthesis of a second strand of viral DNA.

Once the HIV RNA genome has been copied into a double-stranded DNA copy, integration into the host cell chromosome is necessary for the production of viral RNA and proteins. The nucleoprotein complexes, which contain the nascent double-stranded viral DNA (the viral preintegration complexes) of most retroviruses, are unable to traverse the intact nuclear membrane. The replication of such retroviruses, therefore, is restricted to cells that are actively dividing where nuclear membrane breakdown has occurred as in the case of mitosis. The HIVs and other lentiviruses, however, are able to infect some non-dividing cells with intact nuclear membranes, such as macrophages. The exact process by which the HIV nucleoprotein is transported across the nuclear envelope is not yet clear but is known to involve the viral matrix (MA).

Once inside the nucleus, the HIV genome is integrated into the host chromosomal DNA in a stable form known as provirus. This reaction is mediated by the viral integrase protein (IN) which, like RT, is brought into the cell as part of the infecting nucleoprotein complex (Swanstrom & Wehbie, 1999). The integrated provirus serves as the template for transcription of full-length viral RNA transcripts, which contain all the genetic information present in the original RNA genome (Parslow, 1993). The new virions then bud from the host cell. This process can take place slowly, or so rapidly that the host cell ruptures or lyses (Green-Nigro, 1999). The viral replication cycle takes 2 days to complete (Ambrosiak & Levy, 1999).
Most drugs which have been studied to date as inhibitors of HIV-1 replication are directed against viral reverse transcriptase. These include nucleoside (zidovudine or AZT), didanosine (ddI), zalcitabine (ddc), stavudine (d4T) and lamivudine (3TC) and non-nucleoside inhibitors (NNRTIs) such as nevirapine and delavirdine (Feinberg, 1997).

Transmission of HIV/AIDS

HIV is present in all the body fluids of an infected person, including cerebro-spinal fluid, lacrimal fluid, saliva, synovial fluid, breast milk and bone marrow (Cohen, 1991; Hubley, 1995) but it is concentrated in blood, semen and vaginal fluid. In addition, it is present in virtually all body tissues and organs including brain tissue and spinal cord. HIV-1 and HIV-2 are transmitted in the same way:

1. Sexually: The most common route of HIV transmission is by sexual intercourse both heterosexual (between man and woman) and homosexual (between man and man) (Handsfield & Jaffe, 1990; Hubley, 1995). From 1985 to 1990, heterosexual transmission of HIV to women increased in frequency in the United States (Handsfield & Jaffe, 1990; Worth, 1994), in Africa, South America, and Asia, especially Thailand, Myanmar (Burma) and India (Kippax, Crawford & Walday, 1994). By 1992, heterosexual transmission was estimated to account for 65% of HIV infection worldwide and, by the year 2000, this proportion was projected to have increased to 80-90% (Murray & Johnson, 1996; Feinberg, 1997).
2. Parenterally, through blood or blood products: HIV has been transmitted by exposure to contaminated blood or blood products. Blood transfusion from someone who is HIV-infected appears to have almost a 100% probability of transmitting the infection (Kaldor & Rubin, 1994; Perriens & Piot, 1993). Recognition of this has led, in most Western countries, since 1985, to HIV screening programs for blood units and organ tissue donation (Hubley, 1995, Kaldor & Rubin, 1994). Risk is further reduced through the screening of blood donors (Pratt, 1991). Similarly, the sharing of HIV-contaminated needles and syringes is likely to transmit HIV (Abimiku & Gallo, 1995). In South East Asia, especially Thailand, Myanmar, India and Yunnan Province in China, injection by drug abusers is an important route of infection (Hubley, 1995).

3. Perinatally: from infected mothers to their infants in the perinatal period is the third major transmission route (Cohen, 1991). Transmission from an HIV-infected mother to her child, i.e. vertical transmission, accounts for between 12-40% of infections worldwide (Perriens & Piot, 1993). The fetus is infected through the placenta and, the newborn child, through infected vaginal secretions (Ambroziak & Levy, 1999) and, much less commonly, breast milk (Kaldor & Rubin, 1994; Hubley, 1995).

The modes of transmission vary from one geographical region to another. For example, homosexual activities and intravenous drug use are the major means of transmission in developed countries, while heterosexual activities and blood transfusion are the most important modes of transmission in developing countries (Abimiku & Gallo, 1995).
Heterosexual Transmission of HIV Infection

As indicated above, heterosexual transmission accounts for 80-90% of infection worldwide (Stratton & Alexander, 1997). HIV-1 is much more efficiently transmitted from male to female (twenty times greater) as a result of one episode of vaginal intercourse (Feinberg, 1997). In addition, HIV disease progresses three times as fast in women than it does in sociodemographically similar men and the survival time of women is merely one tenth that of white gay men (Feinberg, 1997). This difference in survival times, however, is now considered to be more a function of the Yentl Syndrome (Ayanian & Epstein, 1991), i.e. the differential access of women and men to medical care than to differences in HIV-1 biology (Chaisson, Keruly & Moore, 1995; Clark, 1997). The Yentl Syndrome reflects a recognition of a gender bias in medicine, which results in women having unequal chances of having symptoms taken seriously, appropriate diagnostic testing ordered and the correct diagnosis made.

Infection occurs during unprotected sexual intercourse when cell-free virions attach directly to target cells; it also occurs through macrophage phagocytosis of virus-antivirus immune complexes.

Infection is 2-4 times more likely when heterosexual couples, of whom one partner is infected, engage in anal rather than exclusively vaginal intercourse. This is important; 10% of women in USA engage in unprotected anal sex (often as a means of avoiding pregnancy) and 30-44% of commercial sex workers engage in unprotected anal sex (Stratton & Alexander, 1997).
The increased risk of infection associated with penile-anal intercourse is biologically plausible (Stratton & Alexander, 1997). Firstly, colorectal mucosal cells have CD4 receptors, thus they may be infected directly. Secondly, rectal mucosae are thinner than vaginal epithelia; this implies that mucosal lesions may be produced by the friction of penile-anal intercourse rather more readily than through penile-vaginal intercourse.

Insemination, menstruation and the presence of other sexually transmitted diseases (STDs) all influence the risk of infection (as, of course, does viral load and CD4+ T cell count) from unprotected penile-vaginal intercourse. In terms of insemination, studies demonstrate a reduced rate of seroconversion in HIV-1 positive men who use withdrawal as a means of contraception (Musicco, Nicolos, Saracco & Lazzarini, 1993). This suggests that the acid pH of the vagina may inactivate HIV in the pre-ejaculate. With ejaculation, however, semen neutralizes the pH of the vagina for about 30 minutes to a few hours (Fox, Meldrum & Watson, 1973). This may allow HIV from semen deposited in the vagina to remain viable. In addition, seminal plasma contains many immunosuppressive factors and high levels of prostaglandins, including 19 hydroxyprostaglandin E, a potent inhibitor of human natural killer cell activity (Tarter, Cunningham-Rundles & Koidde, 1986).

HIV is detectable in menstrual blood and having intercourse during menstruation increases the risk of infecting the male partner (European Study Group on Heterosexual Transmission of HIV, 1992). This is thought to be due to menstrual blood raising the vaginal pH to neutral range, which in turn, improves the viability of HIV shed both in menstrual blood and deposited in semen. In addition, the chemical
constituents of blood serve as a potential growth medium for HIV and other STDs and macrophages, granulocytes and lymphocytes can be found in vaginal lumena during menses (Hill & Anderson, 1992).

People with other sexually transmitted diseases are at a higher risk of acquiring HIV infection (Clark, 1997; Sorrell & Kesson, 1996; Stratton & Alexander, 1997). Firstly, these individuals become infected because their behaviours cause an increased incidence of all STDs. Secondly, some STDs, such as gonorrhea and chlamydia, stimulate an increase in inflammatory cells which serve as target cells for HIV. Thirdly, ulcerative STDs, like syphilis, chancroid and herpes simplex virus, disrupt the epithelial or mucous membrane integrity thus increasing the risk of direct inoculation of HIV into the systemic circulation. The recruitment of macrophages and activated lymphocytes to the ulcer base also increases the number of available target cells.

Intact male condoms, both latex and polyurethane, when used correctly and consistently, protect against infection by preventing direct contact between penis and vaginal and cervical secretions and lesions and between penis and rectal mucosae.

It was noted above that women are twenty times more likely to be infected by their male partners than vice versa. This is thought to be a result of two factors. Firstly, the extent of the epithelia in the female genital tract to which HIV/AIDS potentially acquires access and, secondly, the microanatomy of the penile skin. It is covered with cornified stratified squamous epithelium, which uncommonly tears or develops lesions (Stratton & Alexander, 1997). The presence of a penile foreskin, however, increases the risk of infection (Latif, Katzenstein, Bassett, Houston, Emmanuel & Marowa,
This is thought to be due to the trapping of HIV in the protected and moist environment under the foreskin where virus entry into Langerhans cells can occur (Miller, Vogel & Alexander, 1992). In addition, lack of circumcision is associated with an increased risk of other STDs, e.g. chancroid and gonorrhea (Simonsen, Cameron & Gakinya, 1988; Handsfield, 1984).

HIV/AIDS Incidence in Developing and Developed Countries

At the start of the new millennium the AIDS pandemic entered its third decade yet much uncertainty persists with respect to the extent of HIV infection in many countries. Uncertainty also persists with respect to the past, current and future incidence of AIDS and its demographic, social and economic impact on populations around the world (Way, Schwartlander & Piot, 1999). These uncertainties are due to a range of factors: weak surveillance systems; lack of access to appropriate medical care; deficiencies in the diagnosing and reporting of AIDS cases; and, the lack of vital registration systems (Way, Schwartlander & Piot, 1999).

Irrespective of these uncertainties, however, a vast amount of epidemiological information on HIV and AIDS is available. Much of this has been acquired through scientifically designed seroprevalence studies of particular groups and sentinel surveillance systems aimed at monitoring HIV prevalence levels in, for example, antenatal women and people attending clinics for sexually transmitted diseases.

HIV/AIDS incidence is defined as the HIV/AIDS rate of infection in a population. In 1995, the World Health Organization (WHO) estimated that 18 million people were infected with HIV worldwide (Ward & Drotman, 1996) and predicted that by the year
there would be one million new cases annually, that two million will have already died of AIDS and that five hundred thousand new cases of AIDS will be documented each year (Dwyer, Mathathir & Nath, 1997). More recently, however, WHO and the Joint United Program on HIV/AIDS (UNAIDS) estimated that 30.6 million people were infected with HIV worldwide (Way, Schwartlander & Piot, 1999).

Clearly the incidence of new cases has increased dramatically within the last three decades. AIDS is now the number one killer of people between 25 and 44 years (Green-Nigro, 1999). In the mid-1980s, the WHO adopted a framework that reflected the changing dynamics of the pandemic; it classified HIV/AIDS pandemic into three patterns (Mann, Tarantola & Netter, 1992; Piot, Kapita, Ngugi, Mann, Colebunden & Wabitsch, 1992).

In pattern one, in the mid-to late 1970s and mainly in Western urban areas, HIV began to spread predominantly through the sexual activities of homosexual and bisexual men. It was estimated that in some urban areas over 50% of homosexual men had been infected. This pattern was predominant in America, Western Europe, Australia, New Zealand and many urban areas in Latin America. In pattern two, which included the late 1970s and early 1980s, HIV infection was spread by heterosexual transmission, blood transfusion, and needle sharing, even though drug-injecting behaviour was reasonably infrequent. Perinatal transmission was a major problem and HIV-infected women were estimated to slightly outnumber infected men. Pattern two included areas such as sub-Saharan Africa, Latin America and the Caribbean. In pattern three, which began on the mid-1980s, and included Eastern Europe, the Middle East, North Africa and most countries in Asia and the Pacific, HIV was spread mainly through people
with ‘risk behaviours’ such as commercial sex workers and persons with drug-injecting behaviours. The incidence of HIV/AIDS infection is different in developing and developed countries as their socio-cultural and economic situations and health care systems differ.

Early in the pandemic, pattern one was seen, as noted above, in developed countries such as the United States and infection was largely through male homosexual and bisexual contact and intravenous drug injection. For instance, of the 43,000 AIDS cases reported in 1990, only 11% were women (Mann, Tarantola & Netter, 1992), the remaining 89% of infected people were homosexual and bisexual men, injecting drug users and their sex partners. More recently, however, the incidence of new cases of HIV infection among homosexual men has decreased as a result of the impact of AIDS education programs and risk-reducing behaviours, whilst the incidence of HIV infection among drug injectors and heterosexuals has increased (Hubley, 1995). Women currently represent approximately 34% of cases of AIDS spread through heterosexual contact. Fifty-five percent of AIDS sufferers in the United States, however, have been infected by contaminated needles when injecting drugs intravenously (Ancelle-Park & De Vincenzi, 1993).

In Australia, the total number of cases of AIDS reported by the end of March 1996 was 6,730 (National Centre in Epidemiology and Clinical Research, 1996 cited in Kaldor & Crofts, 1997). While the number of new AIDS cases diagnosed in Australia increased rapidly through the mid-1980s, it has been stabilizing over the past six years. Over 90% of HIV cases have been homosexual men (Kaldor & Crofts, 1997).
In Europe, by October 1992, the number of persons with AIDS was 81,849 (European Centre 1992c cited in Ancelle Park & De Vincenzi, 1993). Western Europe, particularly France, Italy and Spain reported the highest number of AIDS cases. As was the case in the United States and Australia, HIV began to spread initially in Western Europe extensively among homosexual men (Mann, Tarantola & Netter, 1992) before extending to heterosexuals and intravenous drug users. Females represent approximately 28% of heterosexual cases of AIDS in Europe but the majority of cases, i.e. 59%, have been infected while injecting drugs (Ancelle-Park & De Vincenzi, 1993).

In Eastern Europe including Russia, HIV infections are still low, with an estimated 3,000 AIDS cases and 50,000 HIV infections (Hubley, 1995).

As indicated above, pattern two is seen predominantly in developing countries; this is because most of the pharmacological treatments now available are beyond the financial reach of these populations (Way, Schwartlander & Piot, 1999). Before the introduction of new drugs in the USA, mortality from AIDS was 80% at 3 years. Mortality could be even higher in developing countries where treatment is virtually non existent. By 1990, it was estimated that 2.5 million people in sub-Saharan Africa were infected with HIV (Haymann, Chin & Mann, 1990). By 1996, according to UNAIDS (Way, Schwartlander & Piot, 1999) 20.8 million Africans were living with HIV and 50% of these were women. The African population is now considered the most vulnerable to future infection (Barnett & Blaikie, 1992), the major routes of transmission being heterosexual sex and vertical transmission from mother to child. When HIV-infected parents become ill and die, many of their children who are infected are confronted with
the disease as well. A study in sub-Saharan Africa found that one out of three children born to an infected mother will be infected (Mann, Tarantola & Netter, 1992). Infant and child deaths due to AIDS, therefore, could significantly increase child mortality rates in Africa.

The main focus of infection in Africa is in East and Central Africa, where between a quarter and one third of adults aged 15-49 years (reproductive age) are estimated to be infected (Hubley, 1995). By 2010, life expectancy in Zambia is expected to fall from 66 to 33 years, in Zimbabwe, from 70 to 40 years and, in Uganda, from 59 to 31 years (Green-Nigro, 1999). Moreover, urban areas exhibit higher infection rates than rural areas, with infection spreading from urban to rural areas as a result of transportation and rural-urban migration (Ancelle-Park & De Vincenzi, 1993; Mann, Tarantola & Netter, 1992). For instance, many people in rural areas, especially men, have been attracted to work in large cities where more favourable employment opportunities exist; whilst these men are far away from their homes and families, they have sex with prostitutes in the city and when they go back home they have sex with their wives (Ancelle-Park & De Vincenzi, 1993).

In pattern three, HIV transmission began in only a few countries in Asia during the late 1980s; however, the incidence of infection has been spreading rapidly since then (Yoddumnern-Attig, 1992b). By 1997, UNAIDS estimated that 6.4 million Asians were living with HIV/AIDS (Way, Schwartlander & Piot, 1999). In Cambodia the epidemic has grown with frightening speed with Vietnam also experiencing a rapid growth in infections (Brown, 1997). India is experiencing the most serious epidemic; it is estimated that more than 2,000,000 people are currently infected (Dwyer, Mathathir
& Nath, 1997). In Burma (Myanmar), it is estimated that there are at least 400,000 infected persons and HIV is spreading rapidly across Burma’s many borders (Dwyer, Mathathir & Nath, 1997). In Thailand, there were over 50,000 infected people in early 1990 (Hubley, 1995); by 2000 this figure had increased to 2 million. Thailand’s AIDS epidemic is now at crisis level and it is the nation’s highest priority public health problem (Voddumern-Attig, 1992b).

In Asia, the most common route of transmission is by heterosexual intercourse. However, until relatively recently the blood supply was unsafe in Japan, where imported blood products received by people with hemophilia formerly represented the main mode of transmission; now it is transmitted mainly by sexual activity (Mann, Tarantola & Netter, 1992).

The alarming spread of HIV has resulted in some Asian countries introducing HIV prevention strategies. For instance, China has introduced HIV educational programs and, in Malaysia, both government and non-government organizations have spent much money to conduct many HIV/AIDS prevention programs (Dwyer, Mathathir & Nath, 1997).

The Incidence of HIV/AIDS in Thailand

The origin of the HIV/AIDS epidemic in Thailand is traced back to a single case of the disease, which appeared in a young homosexual man. He had studied in the United States and was diagnosed with AIDS in 1984; he returned to live in Thailand and to be sexually active (Limsuwan, Kanapa & Siristonapun, 1986; Sittitrai et al, 1992).
However, the epidemic did not take off dramatically until 1988 when it occurred among intravenous drug users (Koetsawang & Auamkul, 1997).

Since 1989, the Ministry of Public Health (MOPH) has conducted an HIV National Sentinel Serosurveillance Survey among specific populations to track the epidemic. The survey reveals that, across time, different population groups demonstrated a rapid increase in the incidence of HIV/AIDS infection in Thailand (Viravaidya et al, 1994). The first such “wave” of infection was among intravenous drug users (IVDUs) (Wawer et al, 1996). In 1987, HIV seroprevalence in this group was 0-1%, rising to 20% in September 1988 (Ancelle-Park & De Vincenzi, 1993; Batterick et al, 1994). In the second wave, HIV infection increasing occurred among female commercial sex workers, with first direct and then indirect CSWs testing positive in large numbers, beginning in 1989 (Batterick et al, 1994). The difference between direct and indirect CSWs is that direct CSW’s service is exclusively sexual; these women always live in brothels and work in or from brothels. In contrast, indirect CSWs are also waitresses, bar girls, attendants in massage parlors, entertainers such as singers, dancers and the like (Kilmarx et al, 1998; Wawer et al, 1996). CSWs, by virtue of their sexual behaviours, are considered more vulnerable to HIV infection than other ‘at risk’ people. The third wave of the Thai epidemic saw the male clients of CSWs becoming infected with HIV-1 subtype E (Brown, Sittitrai, Vanichseni & Thisyakorn, 1994; Kunanusont et al, 1995; Sittitrai et al, 1992; Swanstrom & Wehbie, 1999). Currently, the fourth wave involves the wives or girlfriends of the men who have contracted HIV in the third wave (Brown et al, 1994; Mills et al, 1997). In the last wave of infection, that is the fifth, the children born from HIV-positive mothers contracted the virus (Brown et al, 1994; Rerks-Ngarm, 1997). Neither the fourth nor the fifth wave has
been directly studied; data are available, however, on pregnant women in antenatal clinics. In 1992, HIV prevalence in this group varied from 0 to 7.38% (Batterink et al, 1994), and the rates are believed to have continued to increase since then (Sittitrai et al, 1992).

After the first case of HIV infection was diagnosed in Thailand, the virus spread rapidly throughout the population. By the year 2000, the MOPH, WHO and several Thai NGOs estimate that there will be 2 to 4 million people HIV infected with 350,000 to 650,000 people suffering from AIDS (Cash, Anasuchatkul & Busayawong, 1995). It is possible, however, that the MOPH statistics are low due to underreporting of HIV/AIDS. The actual number of cases of HIV infection is thought to be considerably higher than the number of officially reported cases (Ford & Koetsawang, 1991). On death certificates, for example, the secondary infection, which leads to death, is reported as the cause of death (Batterink et al, 1994).

HIV infections are concentrated among adults between the ages of fifteen and forty-five (Safman, 1996) and, in 1994 in Thailand, 80-90% of AIDS cases were men (Batterink et al, 1994). As the data on the third, fourth and fifth waves indicate, however, Thai women are increasingly at high risk of HIV infection (Cash, Anasuchatkul & Busayawong, 1995).

At the present time, the AIDS situation is most serious in the northern region of Thailand, with the provinces of the upper north, most notably Chiangmai, Chiangrai and Phayao (Batterink et al, 1994; Brown et al, 1994), having the highest rates of HIV infection (Cash, Anasuchatkul & Busayawong, 1995). For instance, in Chiangmai,
prevalence of 1.9% in June 1990 in antenatal clinics increased to 8.0% by December 1993 (Brown et al, 1994).

**Commercial Sex Workers and HIV Infection**

Commercial sex workers are important vehicles for the transmission of HIV/AIDS in developing countries, yet very few prostitutes in Europe are seropositive (Wilson, 1993). Of the few European CSWs who are seropositive, 50% of them are I.V.D.U.s.

The low seropositivity of European CSWs is now considered to be a function of their own highly organized social activism. They have actively and voluntarily instituted risk-minimizing behaviours and insisted on regular HIV/STD screening (Wilson, 1993).

The same level of organized, self-protecting activism is not evident in CSWs in developing countries. In Africa, the infection rates of CSWs is 3-300 times higher than those of pregnant women and 65% of CSWs in Chiangmai (Thailand) were seropositive (Calento, 1994). The vulnerability of CSWs in developing countries is amplified by poverty and limited education; see below.

Due to the long tradition of prostitution of Thailand, both the supply and demand for this service needs to be examined (Viravaidya et al, 1994).

On the supply side, both economic and cultural factors result in large numbers of Thai women becoming sex workers (Ungsongham Hata, 1995) with about 48% coming from the north (Batterick et al, 1994). Studies in the north indicate that approximately
50% of CSWs come from farming families, 16% are formerly labourers and factory workers, and 34% are housekeepers, students or others (Yoddumnern-Attig & Attig, 1993). These women are usually young, 14 to 18 years old, and 80% come from poor rural families (Limanonda, Tirasawat & Chongvatana, 1993). Many northern Thai families are landless, because of the transfer of land from farmers to industrial or housing projects or golf courses, as well as to public projects such as roads and dam construction (Yoddumnern Attig & Attig, 1993). In rural areas, most girls finish six years of compulsory primary school; less than 50% of them continue on to secondary school (Viravaidya et al, 1994). In Limanonda, Tirasawat and Chongvatana’s (1993) study, 87% of CSWs had completed less than 7 grades at school and 25% could not read nor write. To enable girls to continue studying in secondary school, their parents have to pay for school fees, uniforms and books, all at considerable cost. Only 10% of children from rural areas, therefore, continue on to secondary school (Soonthorndhada, 1992).

After primary school, girls in the local area move to work in factories or the construction industry. They cannot find well-remunerated employment in their villages; they migrate to cities, therefore, to seek employment to enable them to send money home to their parents (Wawer et al, 1996). This money often allows their families to buy land, build a new house and purchase consumer goods, such as televisions or motorcycles. Even in rural society, radio, television and motorcycles are common possessions (Taywaditep, Coleman & Dumronggittigule, 1997). A daughter is expected to help care for her parents and younger siblings (Yoddumnern-Attig, 1992c); she is expected to fulfil economic obligations to her family, including “repayment” to her parents and economic support of the younger members of the
family (Cash, Anasuchatkul & Busayawong, 1995; Sittitrai & Brown, 1994). She should be grateful to her parents for raising her; this is called “bunkhun” in Thai (Komin, 1990). Bunkhun is the primary symbol of moral goodness for Thais; it means caring for parents or supporting them financially (Mulder, 1990). This sense of obligation has a long tradition and is seen as valuable for everyone. In addition, Thais believe that the tradition of repayment to parents allows children to gain more merit (Choowattanapakorn, 1999). Indeed, acts of kinship loyalty and filial piety are seen as redemptively merit-making, even for CSWs (Taywaditep, Coleman & Dumronggittigule, 1997). (Interestingly, CSWs are generally condemned not for prostitution as such, but for engaging in extramartial sex (Manderson, 1992).)

Commercial sex work is the most highly paid employment option available to Thai girls and young women and entails less physically demanding work than construction, etc (Yoddumnern Attig & Attig, 1993) and because of this, it is more attractive than the other employment options available to these women (Viravaidya et al, 1994). A conservative national estimate of income for CSWs is 4,000-6,000 Baht ($110-160 US) per month (some can earn much more), compared to 2,500 Baht ($70 US) per month for a factory worker or other unskilled labourer {Viravaidya et al, 1994). The price for having sex with a virgin at a commercial sex establishment is often higher than for non-virgins (Rao Gupta, Weiss & Whelan, 1996).

From 1990 to 1995 the Thai economy grew rapidly (Choowattanapakorn, 1999) with absolute poverty decreasing slightly but with the financial pressure on poor families still continuing. Prostitution, therefore, remained a vital source of income to provide for poor families and to express bunkhun. The situation worsened in 1997 when the Thai economy slumped due to export reduction (Choowattanapakorn, 1999) and Thais
confronted higher living expenses and a huge number of labourers lost their jobs. Prostitution became the only occupational choice for many poor rural northern women.

On the demand side, and as discussed above, it is accepted that Thai males will visit brothels for relaxation after drinking and socializing with friends. A recent study on sexual behaviour reveals that 12% of married men, 50% of formerly married men, and 36% of single men had paid for sex in the past 12 months (Viravaidya et al, 1994). Younger girls are particularly wanted because men consider that they cannot yet be infected with HIV (Batterink et al, 1994).

Also as noted above, there are two types of prostitution. These are direct prostitution and indirect prostitution. The former work in brothels and are required to attend government Sexually Transmitted Disease (STD) clinics, whereas the latter work in bars, massage parlours, etc and do not attend government STD clinics. In addition, the number of indirect CSWs are increasing; this is likely to become an increasing problem in the spread of HIV because indirect CSWs are less consistent in terms of condom use than direct CSWs (Sittitrai, 1996).

Attitudes to women working as CSWs differ from province to province. For example, southern Thai women who become prostitutes need to work clandestinely because their relatives and other local people would disapprove (Songwathana, 1998). In contrast, once northern Thai women who have worked as CSWs have earned enough income, they return to their hometown and marry local men. It is acceptable for former CSWs to return to their villages, to marry and raise a family (Ford & Koetsawang, 1991; Viravaidya et al, 1994). One study of 55 schools in two northern Thai provinces found
that although students were aware that CSWs were apparently negatively stigmatized, they also felt that most men would be willing to marry a CSW when she returned home (Gilmore & Somerville, 1994). In the northeast province, in contrast, women working as CSWs is reluctantly tolerated as a way of coping with a family's poverty, whilst in the South, as indicated previously, negative sanctions are strong (Ford & Koetsawang, 1991).

It does appear, however, that the fear of HIV has led to a reduction in prostitution in Thailand; it was estimated in 1994 that the Thai CSW population had declined by 23% (Hanenberg & Rojanapithayakorn, 1998). This is due to both a reluctance on the part of young women to become prostitutes and a reluctance on the part of young men to visit them (Hanenberg & Rojanapithayakorn, 1998) possibly as a result of government educational campaigns in schools and universities. In addition, there is evidence that public health programs in Thailand have led to 20% reductions in the use of CSWs, a 30% increase in the consistent use of condoms and a 30% decrease in the incidence of STDs in young men (Nelson, 1996). Interestingly, and somewhat ironically, as the number of Thai CSWs decrease, the number of CSWs from bordering Asian countries, e.g. Myanmar, increases (Hanenberg & Rojanapithayakorn, 1998); CSWs, therefore, remain a culturally important component of Thai society.

**Condom Use**

The spread of HIV by female CSWs has been associated with the low use of condoms (Nagachinta et al, 1997); education and prevention programs, therefore, are extremely important. The biggest HIV/AIDS Prevention and Control Program conducted by both government and non-government agencies aims to raise awareness of the dangers of
AIDS and to reduce risky behaviour; it also aims to provide care to people suffering from AIDS (Rojanapithayakorn & Hanenberg, 1996). Since the major mode of transmission in Thailand is now heterosexual transmission through CSWs, the HIV/AIDS Prevention and Control Program promotes condom use with CSWs (Mastro & Limpakarnjanarat, 1995; Rojanapithayakorn & Hanenberg, 1996).

Since Thai government (and non-government) organizations began to promote the “100% Condom Campaign” for AIDS protection in 1989 (Nelson, 1996: Ungphakorn & Sittitrail, 1994), the number of condom users has risen and the use of condoms for sex with CSWs has become the norm in Thailand (Rojanapithayakorn & Hanenberg, 1996). As a result of this campaign some northern brothels have introduced “no condom, no sex” policies (Ungsongtham Hata, 1995), and it has been claimed that this has prevented over 2 million HIV infections in Thailand (Robinson, 1996). It has been reported, for instance, that the percentage of commercial sex acts using a condom increased from approximately 25% in June 1989 to over 90% in December 1994 (Mastro & Limpakarnjanarat, 1995; Rojanapithayakorn & Hanenberg, 1996). Condom use, as already noted, with indirect CSWs is significantly lower than with direct CSWs, non-use of condoms being reported in between 1.1% (massage parlours) to 26.9% (restaurants) (Brown, 1996).

Interestingly, Thai clients of CSWs are twice as likely to engage in unprotected sex with truck drivers and men from the general population reporting, respectively, 51% and 53% consistent condom use (Pramualratanan, 1994) than non-Thai clients (Brown, 1996).
It should be noted, however, that there is some ambivalence in relation to the use of condoms, which results in unnecessary exposure to infection. In general, the use of condoms is seen to imply that women are bad or unclean, or that wives do not trust their husbands (Yoddernmn-Attig & Attig, 1993). Condoms are generally considered more suitable for CSWs or casual partners than for sex within a relationship (Sittitrai & Brown, 1994) or even with regular clients (Brown, 1996). It appears that the non-use of a condom is a very important symbol of trust in the relationship (Wawer et al, 1996) and wives often have very little power within their relationships to insist on condom use (Heise & Elias, 1995; Gaskins, 1997).

In addition, the clients of CSWs who refuse to use condoms and sometimes even offer to pay more for unprotected sex have been exempt from criticism (Ungsongtham Hata, 1995) and 67% of CSWs said they would have sex with a man even if he refused to wear a condom (Yoddummn-Attig & Attig, 1993). This willingness of Thai CSWs to expose themselves unnecessarily to infection contrasts starkly with CSWs in Europe. Whether it is a function of the pressure of bunkhun, the inferior status of women relative to men or lack of education, both general and AIDS-related, or a combination of all three remains a moot point. What is certain, however, is that as long as CSWs remain willing to expose themselves to infection, they will remain a dangerous reservoir for HIV/AIDS infection in Thailand.

Refusal to wear a condom has been associated with drunkenness and this is important; 35% of men in the North reported normally drinking before visiting a prostitute, and CSWs report difficulty in insisting that drunken clients use condoms (Sittitrai & Brown, 1994). Other reasons for the non-use of condoms include: condoms do not feel
“natural”; the men thought that the sex workers were disease-free; there is no condom available; discomfort and pain from insufficient lubrication; perception of the client as not HIV infected; client refusal; CSWs need for money (Sittitrai & Brown, 1994; Wawer et al, 1996); and, client preference for sex with younger girls supposed to be virgins, whether CSWs or not (Batterink et al, 1994). As long as such ambivalence to condom use with both CSWs and girlfriends/wives prevails, HIV/AIDS will continue to spread in Thailand.

Summary

HIV/AIDS is caused by two retro (lenti) viruses, HIV-1 and HIV-2. HIV-1 was identified in 1983 and, HIV-2, in 1985; the disease was first recognized in 1981 when three gay men presented with severe immunosuppression, pneumocystis carinii pneumonia (PCP) and Kaposi’s sarcoma. HIV-1 and HIV-2, like all retroviruses, are enveloped, single-stranded RNA viruses which enter host cells via CD4 receptors. These are found mainly on T helper cells, macrophages, monocytes and glial cells. Mature CD4+ cells are central to efficient immune response; their depletion, therefore, leads to severe immunosuppression.

HIV/AIDS is present in all body fluids of infected people; it is concentrated, however, in blood, semen and vaginal fluid. The disease is spread sexually, through both homosexual and heterosexual intercourse, parenterally, through blood and blood products and perinatally, from mother to child. Modes of transmission differ geographically. Homosexual intercourse and intravenous drug use are the main means of transmission in developed countries, while heterosexual intercourse and blood transfusion are the most important modes of transmission in developing countries.
number of women infected with HIV/AIDS is increasing world-wide; this is especially the case in developing countries.

It has been estimated that 30.6 million people are infected with HIV/AIDS world-wide; it is now the number one killer of people between 25-44 years. The World Health Organization has classified the pandemic into three patterns. Pattern one, in the 1970s, affected homosexual and bisexual men mainly in Western urban areas. Pattern two, in the late 1970s and 1980s, saw the spread of the disease through heterosexual and perinatal transmission, blood transmission and needle sharing, in Africa, Latin America and the Caribbean predominantly. HIV infected women were estimated to slightly outnumber men. Pattern three, which began in the mid-1980s, affected Eastern Europe, the Middle East, North Africa, the Pacific and Asia. Transmission in Pattern three was mainly by CSWs and drug-injecting behaviours. Sexual transmission may be prevented through the use of latex and polyurethane condoms.

The first case of HIV/AIDS in Thailand was diagnosed in a young homosexual man in 1984. The Thai epidemic took hold in 1988 through IVDUs and it is currently estimated that 2-4 million Thais are infected. The Ministry of Public Health has classified the Thai epidemic into five waves: the first wave saw spread in IVDUs; in the second wave, infection spread among direct and indirect CSWs; in the third wave, the disease spread to the male clients of CSWs; in the fourth wave, to the wives of CSW clients; and, in the fifth wave, to the children of infected women.

Commercial sex workers and attitudes to condom use remain important factors in Thailand’s continuing epidemic. Commercial sex workers are mainly young women
from poor farming communities, who have had little general education and feel the need to express *bunkhun* to their families. A number of them, especially indirect CSWs, remain willing to engage in unprotected sex with clients, despite the government's "No condom, no sex" campaign. In addition, some Thai men resist the use of condoms on comfort and pleasure grounds. Finally, both women and men construe the use of condoms as inappropriate for intra-marital sex; their use signifies a lack of trust. As long as these attitudes and behaviours persist, however, HIV/AIDS will continue to spread in Thailand.
Chapter Three

The Impact of HIV/AIDS on Infected People

Introduction

In order to understand the impact of HIV/AIDS on Thai women’s lives it is first necessary to consider the impact of the disease more generally. Accordingly, this chapter focuses on the clinical and psychosocial manifestations and implications of the disease, in relation to HIV/AIDS infected people in general, and in relation to infected Thai women, in particular. It also focuses on the psychosocial tasks which HIV/AIDS infected people must address to manage their disease and what factors assist them to do this.

More specifically, the chapter begins in a discussion of the stages of HIV pathogenesis which HIV infected people experience and the symptomatology which typifies each stage. This discussion highlights differences in symptomatology experienced by women and men. The chapter then continues with a discussion of the psychosocial implications of HIV/AIDS for infected people more generally, and for Thai women in particular. HIV/AIDS is characterized as a disease of profound loss. The chapter terminates, rather more positively, in a discussion of the factors which assist HIV/AIDS infected people in general, and Thai women in particular, to cope with and manage their disease. Strong familial and extra-familial social support networks, which include membership of Persons With AIDS Groups, are identified as critical to the adequate management of HIV/AIDS.
Stages of HIV Infection

The pathogenesis of HIV infection can be considered as progressing through three (Ambroziak & Levy, 1999), four (Peters, 1996) or five stages (Wright, 1996). All these models will be discussed in this section, beginning with the three-stage model. Clearly, there is considerable overlap between the models.

During the initial acute infection, or early stage, i.e. typically two to four weeks from infection (Tyndall & Cooper, 1996), many CD+ T cells and some macrophages are infected and HIV replication produces high viremia, up to 5000 particles / ml plasma. During this stage, before an immune response can be mounted by the host, lymphoid tissues and other cells in the body become infected. As many as 250 billion cells could be infected in this early period. CD4+ T cells decrease and CD8+ cells increase; the person converts to seropositive HIV status.

Clinical manifestations in the early stage of disease differ from person to person (Green-Nigro, 1999). Many present with a mononucleosis-type illness with fever (97%), fatigue, arthralgia (58%), pharyngitis (73%), myalgia, oral and oesophageal candidiasis, nausea, headache and axillary, cervical or general lymphadenopathy (77%). Some will present also with an HIV erythematous non-pruritic maculopapular rash on trunk and body, others with oesophageal or anal canal ulcers, and diarrhea. Others will present with central nervous system disorders such as irritability, mood changes and depression since lentiviruses are neurotropic and potentially neurovirulent (Ambroziak & Levy, 1999; Green-Nigro, 1999). Acute febrile pharyngitis is the most common initial, presenting symptom (Valle, 1987) although 30% of IVDUs will present with bacterial pneumonia. These symptoms usually present within one to three
weeks of infection and normally subside within a few weeks, when the host's immune response becomes effective, although lymphadenopathy, malaise and fatigue, often severe, may persist for months (Koenig & Fauci, 1999; Tyndall & Cooper, 1996). HIV enzyme immunoassay (EIA or ELISA) which screens for HIV antibodies usually become positive within 4-8 weeks of acute illness. The period between infection and positive EIA is known as the "window period" (O'Keefe & Walker, 1992).

Several months after primary infection the second or asymptomatic stage begins. This can last from about one year to a decade (Tyndall & Cooper, 1996). HIV accumulates in lymphoid tissue organs and replicates despite a low viral burden (Pantaleo, Graziosi & Demarest, 1993) and the number of CD4+ cells often begins a slow decline. Nevertheless, the virus is somewhat controlled during this stage, presumably by CD8+ cell antiviral activity. Eventually, however, depleted CD4+ cell levels and increased viral load lead to the final or symptomatic stage. Depleted CD4+ levels are thought to reduce CD8+ antiviral immune responses since CD8+ cell function depends on a product (IL-2) of CD4+ cells (Ambroziak & Levy, 1999).

Tuberculosis is an important pulmonary problem of HIV/AIDS; it can be the first clinical manifestation or can be present at different stages of HIV infection (Smith & Pigott, 1997).

It is estimated that about 70-80% of HIV infected persons are asymptomatic in any one period (Bartlett & Finkbeiner, 1996) with the only clinical signs of the disease being dermatologic manifestations such as seborrheic dermatitis (DeHovitz, 1995). When CD4+ counts are below 500 (the normal count is between 500 and 1,400 CD4 cells per
millilitre of blood) infected people become symptomatic (Bartlett & Finkbeiner, 1996). CD4+ counts below 200 / mm$^3$ of plasma are considered end-stage disease or AIDS (Koenig & Fauci, 1999).

The common clinical manifestations of the third stage of HIV infection include thrush, oral hairy leukoplakia, shingles, idiopathic thrombocytopenic purpura and constitutional symptoms which include chronic fever, weight loss, malabsorption and chronic diarrheá (Bartlett & Finkbeiner, 1996). These end-stage gastrointestinal symptoms, i.e. weight loss, malabsorption and diarrhea are what Africans call “slim disease” (Ambroziak & Levy, 1999). Other common viral manifestations such as herpes simplex and herpes zoster also appear (DeHovitz, 1995).

In addition, infected people with a CD4+ count of between 50 and 200 are at a high risk of developing PCP (90%), toxoplasmosis, lymphoma (25-35%), and cryptococcal meningitis (DeHovitz, 1995; Lipman & Johnson, 1993; Wright, 1996). Herpes simplex virus infections and Kaposi’s sarcoma also occur (DeHovitz, 1995; Lipman & Johnson, 1993; Pozniak, 1993; Worth, 1994).

**Clinical Manifestation of HIV Infection in Women**

The clinical manifestations of HIV infection in women can differ from those of men. Women with HIV infection often have gynecological problems (Bartlett & Finkbeiner, 1996; Gaskins, 1997), the most common manifestations in early disease being vulvovaginal candidiasis, pelvic inflammation and cervical dysplasia (DeHovitz, 1995; Sabo & Carwein, 1994; Worth, 1994). They are also 5-10 times more likely to develop pre-invasive cervical carcinoma than non-infected women (Wright, 1996). In
end-stage disease, women also complain of gynecological problems. These include changes in menstrual cycle patterns and increased premenstrual symptoms; their pre-invasive cervical cancer is also likely to progress to an aggressive invasive cervical carcinoma (Wright, 1996). In addition, in end stage disease, herpes simplex virus infections occur frequently; men are infrequently infected. In contrast, however, few women develop Kaposi’s sarcoma, which is a relatively frequent development in end stage disease in men.

The three stages discussed above are reflected in the Centres for Disease Control and Prevention in the USA revised HIV classification for adults and adolescents (1993). Their revised classification includes both laboratory and clinical categories.

In terms of their Laboratory Categories, Category 1 includes persons with a CD4+ cell count of 500 or above; Category 2, CD4+ counts of between 200 and 499; and, Category 3, CD4+ counts of less than 200 (see above).

In terms of their Clinical Categories, Category A includes people with (a) symptomatic HIV infection, (b) acute (primary) HIV infection or history of acute (primary) infection and (c) generalized lymphadenopathy. Category B includes people with symptomatic HIV disease who are not classifiable as Category C. Category C includes any with a condition listed in the 1987 surveillance case definition for AIDS (Green-Nigro, 1999).

As indicated above (p. 58), the natural history of HIV/AIDS can also be characterized as having four and five stages. The 4 stage model (Peters, 1996) represents the natural history of HIV/AIDS as primary infection, asymptomatic disease, lymphadenopathy,
and lastly, AIDS or AIDS Related Complex (ARC). In terms of the 5 stage model (Wright, 1996), the clinical manifestations and CD4 cell count ranges thought to typify these stages are presented in table 1 below:

**Table 1**  
Clinical stages of HIV-1 disease and their characteristic clinical presentation and CD4 cell count ranges

<table>
<thead>
<tr>
<th>Stage HIV disease</th>
<th>Clinical presentation</th>
<th>Usual CD4 cell count per µl</th>
<th>Usual duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seroconversion</td>
<td>Fever, pharyngitis, rash, fatigue, mucocutaneous ulcers, lymphadenopathy, headaches, meningitis, encephalitis, neuropathies</td>
<td>150-800</td>
<td>3-14 days</td>
</tr>
<tr>
<td>Asymptomatic</td>
<td>Lymphadenopathy</td>
<td>&gt;300</td>
<td>2-10+ years</td>
</tr>
<tr>
<td></td>
<td>Headaches</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Early symptomatic</td>
<td>Recurrent varicella-zoster</td>
<td>150-500</td>
<td>1-5 years</td>
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<tr>
<td></td>
<td>Oral candidiasis</td>
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<td></td>
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<tr>
<td></td>
<td>Oral hairy leukoplakia</td>
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<tr>
<td></td>
<td>Seborrheic dermatitis</td>
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<tr>
<td></td>
<td>Psoriasis</td>
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<td></td>
<td>Unexplained fatigue, fever, sweats, weight loss, diarrhea</td>
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<td></td>
<td>Vaginal candidiasis</td>
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<td></td>
<td>Cervical carcinoma in situ</td>
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<tr>
<td></td>
<td>Recurrent pelvic inflammatory disease</td>
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<td></td>
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<tr>
<td></td>
<td>Tuberculosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage HIV disease</td>
<td>Clinical presentation</td>
<td>Usual CD4 cell count per µl</td>
<td>Usual duration</td>
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<td>-------------------</td>
<td>----------------------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>Late symptomatic</td>
<td>Kaposi’s sarcoma</td>
<td>50-200</td>
<td>1-4 years</td>
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<td></td>
<td>Lymphoma</td>
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<td></td>
<td>Pneumocystis carinii pneumonia</td>
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<td></td>
<td>Toxoplasmosis</td>
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<td></td>
<td>Esophageal candidiasis</td>
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<td></td>
<td>Cryptococcosis</td>
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<tr>
<td></td>
<td>Recurrent herpes simplex virus infection</td>
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<tr>
<td></td>
<td>HIV-1 associated dementia</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>complex</td>
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<td></td>
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<tr>
<td></td>
<td>Progressive multifocal leukoencephalopathy</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Tuberculosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Pre invasive cervical cancer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advanced</td>
<td>Cytomegalovirus retinitis</td>
<td>&lt;50</td>
<td>&lt;2 years</td>
</tr>
<tr>
<td></td>
<td>Invasive cervical cancer</td>
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</tbody>
</table>

(adapted from Wright, 1996; p 17)
The Psychosocial Impact of HIV/AIDS, in General

Relatively little attention has been focused on the psychosocial implications of HIV/AIDS infection in the developed world; scientists and policy brokers have focused primarily on identifying the causative agent(s) and curative treatments. Even less attention has been focused on the psychosocial effects of HIV/AIDS in developing countries where the development of preventive strategies have been considered the priority (Chesney & Folkman, 1999). In addition, in some developing countries, e.g. Thailand, the “caring” component of HIV/AIDS treatment is generally considered to be the responsibility of family and friends (De Bruyn, 1992) with health professionals concentrating on “curing”. This is unfortunate; HIV/AIDS is an incurable and progressively debilitating disease when inadequately treated (or not treated at all) and, almost invariably, a seriously stigmatizing disease (Chesney & Folkman, 1999).

The psychosocial problems faced by Persons With AIDS (PWAs) are largely a reflection of the social stigma which has been associated with the disease and which arises from intense anxiety about its contagious effects. Such anxieties are fuelled by distorted media coverage which generates public hysteria and encourages discrimination against PWAs and their families (Green, 1988).

HIV/AIDS is a disease of loss (Chesney & Folkman, 1999; Green, 1996; Kubler-Ross, 1987; Munjas, Oliver & Luna, 1998) the psychosocial effects of which are worse than other chronic incurable diseases because it is a seriously stigmatizing disease (Chesney & Folkman, 1999; Sherr & Green, 1996). The losses to which people with HIV/AIDS must adapt include: loss of certainty related to expected life span, activities and the future; loss of social and sexual relationships due to discrimination or fear of
discrimination and progressive dysphoria; loss of status due to loss of social roles and employment; loss of financial security due to employment disruptions and loss; loss of body image and attractiveness due to the physical ravages of the disease; loss of control due to the physical and cognitive ravages of the disease; loss of dignity and privacy; and, loss of watching children grow, achieve and flourish (Munjas, Oliver & Luna, 1998; Sherr & Green, 1996).

What the above implies is that people with HIV/AIDS undergo radical alterations in their sense of self. PWAs feel that they look, act and are different from what they were prior to their infection. A person’s identity is constructed in large part through the roles s/he occupies, i.e. mother, teacher, cook, seamstress, gardener and as the performances of these roles change precipitously so, too, does the PWA’s self image. Role disruption experienced by women may be particularly problematic given their traditional role expectations in relation to family and friends; it can reinforce the women’s already potent feelings of being “unlovable, dirty, unwanted and undesirable” (Hankin, 1993, p 30). Loss of social role, together with fatigue, medical restrictions and changes in physical and cognitive functioning can lead to PWAs limiting their social participation.

In addition, forced retirement from work, separation or loss of intimate relationships, decreased physiologic and cognitive functioning are normally associated with late maturity. Typically, however, HIV/AIDS infects people between 25-45 years (see above); this means that PWAs must confront the tasks of a much later developmental period, without adequate opportunities to master the life tasks of young adulthood. Little wonder, then, that all HIV positive people experience anxiety, that is, a vague,
unpleasant feeling, with a source that is non-specific or unknown. It is experienced by the person as fear and can be mild, moderate, severe, or panic (Munjas, Oliver & Luna, 1998). Levels of anxiety are increased at times of crisis (Green, 1996), for example, at diagnosis, when the disease becomes symptomatic, when loved ones and friends with HIV/AIDS die, etc. (Duffy, 1994; Munjas, Oliver & Luna, 1998).

Anxiety generally has four components. It has a somatic component, e.g. tightness of chest, a cognitive component, e.g. preoccupation with dysphoria, an affective component, e.g. panic, feeling out of control and a behavioural component, e.g. avoidance of particular situations (Green, 1996).

Psychosocially, HIV/AIDS is best characterized as an “emotional roller coaster” (O’Dowd, 1988) which begins at diagnosis and continues until death. The roller coaster is a function of the fears to which PWAs are vulnerable and the stigma with which the disease is associated. These fears and HIV-associated stigma are responsible for the shock, denial, anger, chronic sadness, and sometimes, suicidal ideation (Sangchart, 1998) which PWAs experience. In addition, some PWAs feel a sense of guilt; they question whether their infection represents retribution for past moral, religious or sexual transgressions (Kassel, 1991).

Shock

Most people respond to a positive HIV/AIDS diagnosis with intense shock (Kubler-Ross, 1987); indeed, it may be of a magnitude that impedes the processing of a range of sensory information, including post-test counseling information (Chesney & Folkman, 1999). Shock is usually immediate (Jaccard, Wilson & Radecki, 1995) and
may be amplified in people, particularly women, who have never considered themselves to be at risk (Dowling, 1994). The initial shock and numbness, however, usually resolves reasonably rapidly (Chesney & Folkman, 1999) to be followed, typically, by denial.

Denial

HIV sufferers frequently refuse to accept their diagnosis (Richardson, 1989), denial being the most frequent response to an AIDS diagnosis (Andrews & Novick, 1995; Hayman & Buhrich, 1994; Ross, 1997). Denial is an important defense mechanism which enables PWAs to protect themselves from the reality of the situation (Saylor, 1995). Denial can provide patients with the time needed to assimilate the impact of this disease (Saylor, 1995), and, as it is gradually relinquished, patients begin to confront the reality of AIDS (Kabn, 1995).

Anger

Anger is a strong, uncomfortable, emotional response to a perceived unfairness (Davila, 1999) which is experienced by many HIV infected people who feel very angry with their situation (Bor, 1993; Followfield, 1996). The most common question that HIV-infected people ask is “why me?”. One reason for their anger is the feeling of unfairness that they have become infected (Andrews & Novick, 1995; Bartlett & Finkbenier, 1996). This anger inhibits daily functioning and affects the family life, the social relationships, and the work responsibilities of HIV-infected people (Kabn, 1995).
Women’s experiences and expression of anger may differ from those of men; two factors are considered as possibly explanatory. The first is that anger suppression among women is consistent with female psychological development. The second, and related to this, is that women’s gender role socialization focuses on a sense of self that is grounded in the motivation to initiate, maintain and improve their relationships with others (Davila, 1999). HIV-infected women are frequently angry with their husbands who have infected them with HIV. These women are also likely to feel angry at themselves (Andrews & Novick, 1995) because they internalize rather than externalize their anger (Kabn, 1995).

Fear

Fear is a response to a real or perceived danger (Carpenito, 1993) and the normal human response to fear is “fight or flight” (Munjas, Oliver & Luna, 1998). This response acts as a direct outlet for the physiological and psychological tension arising from fear.

PWAs suffer from a range of fears. They fear that they have or may infect partners and children (Chesney & Folkman, 1999). They also fear symptoms that may or may not be serious (Bartlett & Finkbeiner, 1996).

Clearly, also, given that HIV/AIDS is perceived as incurable, PWAs fear that they will die (Andrews & Novick, 1995; Bartlett & Finkbeiner, 1996); their fear of dying, however, is not as great as their fear of dying slowly and painfully (Richardson, 1989). Other fears include fear of advancing disease, loss of function and loss of home and/or financial security (Beedham & Barnett, 1995). PWAs particularly fear rejection by
loved ones and social isolation (Munjas, Oliver & Luna, 1998). In addition, HIV-infected women who have children are afraid of what will happen to their children after they become incapacitated or die (Richardson, 1989).

**Stigma**

The term stigma originates from the Greek and refers to a tattoo mark branded on the skin of an individual as a result of an incriminating action (Crawford, 1996). Stigma is a universal phenomenon; every society stigmatizes certain people (Saylor, 1995). Goffman (1974) defines stigma as something which disqualifies an individual from full social acceptance and he identifies three types of stigma. The first is the stigma associated with physical deformities and, the second, with character blemishes. Both types of stigma can affect the life of HIV-infected people, their partners, family and friends (Alonzo & Reynolds, 1995; Weitz, 1990). HIV/AIDS infected people are particularly vulnerable to the second type of stigma since AIDS is believed to be a sign of a “blemished character” (Weitz, 1990). The degree of stigma expressed toward individuals with AIDS is greater than toward individuals with other illnesses (Crawford, 1996). Finally, there are the stigmas associated with racial or ethnic origin; these are normally known as prejudice.

At the present time it is broadly accepted that HIV/AIDS infection is a severely stigmatizing disease (Chesney & Folkman, 1999; Crock, 2000; Gilmore & Somerville, 1994; Moneyham, Seals, Demi, Sowell, Cohen & Guillory, 1996; Richardson, 1989; Sherr, 1995); most HIV-infected people report that their lives are affected by both discrimination from others and the fear of such discrimination (Green, 1995). They feel isolated and alone and keep their infection secret for fear of discrimination against
themselves or their families (Broun, 1999; Campbell, 1990). Families also fear rejection or abandonment by friends, neighbours, co-workers and employers; they also feel, therefore, that they need to keep the diagnosis secret from others (Stulberg & Buckingham, 1988).

HIV-infected women may be particularly vulnerable to stigma for a number of reasons (Moneyham et al, 1996). First, the majority of women are infected with HIV through intravenous drug use or sexual activity, behaviour usually discredited by society. Second, many HIV-infected women live in poverty and belong to minority groups. Third, these women often lack a social support network. In addition, feelings of embarrassment are common for HIV-infected women (Broun, 1999) for even when a man may be suffering from AIDS, it is his wife who feels most ashamed of their situation (Broun, 1999).

**Depression**

The term depression is used variously to describe feelings (sad, blue, depressed), symptoms (lethargy, anorexia, insomnia) and mood disorders (major depressive disorder, bipolar disorder). It is a disturbance of mood, which is an elaboration of grief and a reaction to an actual, threatened or perceived loss (Munjas, Oliver & Luna, 1998).

PWAs frequently complain of feeling depressed (see the losses to which they must adapt, above) and clinical depression is the most frequently diagnosed psychiatric disorder in PWAs (Miller & Riccio, 1990; Rabkin & Ramien, 1995). Clinical depression goes beyond grief in terms of both duration and intensity and is
progressively incapacitating (Peternelj-Taylor & Hartley, 1993). It impairs judgement, physical and mental functioning and coping (Munjas, Oliver & Luna, 1998).

**Suicide**

Many studies confirm that HIV-infected people are at an increased risk for suicide (Cote, Biggar & Dannenberg, 1992; Pugh, O’Donnell & Catalan, 1993); PWAs have a suicide rate 40-66 times greater than that of the general population (Munjas, Oliver & Luna, 1998). There are three periods when HIV-infected people are likely to attempt suicide. First, in the early stages of the disease as an impulsive response to emotional distress. The second period occurs when formerly asymptomatic disease becomes symptomatic and, the third, in the late stages of HIV infection when central nervous system complications of AIDS develop (Hayman & Buhrich, 1994; Munjas, Oliver & Luna, 1998). The risk of suicide is especially high when the illness includes a psychiatric disorder (Cote, Biggar & Dannenberg, 1992). Other factors which may contribute to suicidal tendencies include premorbid personality, inadequate counseling and support and inadequate coping skills (Greenfield, 1989; Hayman & Buhrich, 1994; O’Dowd & Zofnass, 1991).

**How People Cope with HIV/AIDS, in General**

Facing the reality of HIV infection is extremely challenging psychosocially for HIV infected people and their families. Allers and Katrin (1988, cited in Kassel, 1991) have suggested that such people must address themselves to five psychological tasks if they are to manage their disease. These tasks are: overcoming initial fear; modification of lifestyle; redefinition of relationships; re-evaluation of the meaning of life; and, adjustment to physical and social limitations. Chesney and Folkman (1999) suggest
that PWAs need two types of strategies to deal with these issues. These are emotion-focused coping strategies (e.g. meditation, relaxation) and problem-focused coping strategies (e.g. problem-solving specific HIV/AIDS related issues). In addition, they also emphasize the importance of maintaining physical health through herbal remedies, diet, rest, meditation and avoidance of alcohol and tobacco.

The cumulative psychological and social losses to which HIV positive people must adjust represent chronic and significant stressors which may in turn adversely affect the immune system (Irwin, Daniels & Bloom, 1987; Perry & Fisherman, 1993). Longer-term survival with HIV/AIDS has been strongly associated with pre-morbid personality, coping skills and strong social support networks (Greenfield, 1989). PWAs live longer and more satisfying lives when they actively maintain good relationships with others, maintain intimacy until death and ask for and receive medical and emotional support (Greenfield, 1989). In contrast, however, PWAs die earlier if they have few or poor and destructive relationships, are passive and submissive and communicate less with health care professionals. The quality of relationship with spouse and family are clearly of critical importance to longer-term survival (Bor, 1993); however, another critically important component in a PWAs social network is access to a HIV/AIDS Support Group (Barough, 1992; Friedland, Renwick & McColl, 1996).

HIV/AIDS Support Groups have three important benefits for HIV/AIDS subjects. Firstly, PWAs benefit from hearing the experiences of others; they feel they are not alone with HIV/AIDS. Secondly, they provide a place to receive and give help when dealing with problems, medications etc. PWAs feel that they can be absolutely honest
with other PWAs about both their problems and their feelings. Thirdly, they provide a source of friends and a safe environment; the Support Group is a place where PWAs can share things that cannot be shared anywhere else, even with close family (Broun, 1999; Maasdorp & Long, 1998).

The one thing that I get out of the support group that I don’t get anywhere else is that it’s a place to go where I can just be, and not have to say something on a bad day. They’ll understand, without a doubt, and I can just be there. Through my action, or through my eyes, without ever saying anything, I can get a hug, or I can just sit there and be with the people who I know will understand. There is no other place I can get that from. There’s just no other place.


The Psychosocial Impact of HIV/AIDS on Thai Women, in Particular

Studies into the psychosocial impact of HIV/AIDS on Thai women indicate that it is similar to the impact elsewhere, in men and women, in other affected groups (Lamping & Sachder, 1993). Thai women, too, experience an emotional roller coaster (see above, p. 67), which includes shock, denial, anger, fear and anxiety (Kongsuriyanavrin, 1997). Despite this, however, infected Thai women, as kulasatrii, still feel an obligation to look after themselves and their families (Broun, 1999). They also shoulder the burden of nursing sick husbands and economic hardship (Soonthordhada, 1992).

Two Thai studies are of particular relevance here. The first study, by Kongsuriyanavrin (1997), demonstrates the particular concerns of HIV/AIDS infected Thai women. First, they feared that they may infect their male partners and children. Second, they
were concerned with their own health and worried that they might die earlier than they expected. Third, they were afraid that they might have frightening and debilitating symptoms or experience pain and suffering before dying. Fourth, they feared that others might find them repugnant when they became aware of their diagnosis because HIV infection is perceived as punishment for immoral behaviour (Seeley & Kajura, 1995). Fifth, these women also worried that they would not be able to fulfil their roles as mothers and wives.

In the second study (Wattanafilin, 1996), infected women were very angry with their husbands for having infected them. They felt that their husbands had behaved irresponsibly by having sex with CSWs.

As in the case of PWAs more generally, the psychosocial impact of HIV/AIDS is due mainly to its stigmatizing effects; these, in turn, lead to social isolation and financial hardship.

**Social Stigma**

Many Thais still continue to stigmatize HIV-infected persons. AIDS is still seen as a disease associated with dirt, danger and death, and as involving physical lesions which differentiate it from others (Songwathana, 1998). In Songwathana's study, 25% of participants said that people with AIDS were the offenders and should be blamed, and 14% said that they had no sympathy for infected persons. As in the generation of discrimination elsewhere, negative and sensationalized media coverage of the epidemic is to be blamed. The media still portrays HIV/AIDS as an incurable disease, which is caused by promiscuity (Songwathana & Manderson, 1998). Discrimination
in Thailand is worse for infected people who have clinical manifestations of the disease such as skin lesions; these unfortunates face automatic stigmatization and discrimination (Baterink et al, 1994).

In the upper north fear of stigmatization and discrimination from the community leads many HIV-infected people to isolate themselves socially (Natpratan, 1998). In addition, in the upper north, other family members (parents and children) are also stigmatized (Fordham, 1993).

The level of stigma to which an HIV infected person is subjected, unsurprisingly, is associated with the mode of transmission. For instance, housewives infected from husbands, children from their mothers and persons who have acquired HIV from blood transfusions suffer the least stigmatization from other villagers. In addition, the stigma of AIDS varies with knowledge level (Songwathana, 1998). For example, those who know more about AIDS have less fear and stigmatize less than others.

Stigmatization violates a fundamental Thai norm, that is “kreng jai” (Komin, 1990), a concept that was introduced above. Kreng jai’s closest meaning in English is “to be considerate; to feel reluctant to impose upon another person; to take another person’s feelings into account; or to take every measure not to cause discomfort or inconvenience for another person” (Komin, 1990 p. 164). Kreng jai is essential to family and social interaction in Thai culture (Bechtel & Apakupakul, 1999). Thai social interaction is structured through the expression of kreng jai with different persons, using different degrees of familiarity and in different situations (Komin,
1990). It can be used to limit the ostracism of those with HIV infection by allowing them to remain in their villages (Songwathana, 1998).

**The Economic Impact of HIV/AIDS on Thai Women**

The economic impact of HIV/AIDS on Thai women and their households can be considerable and accumulative (Manopaiboon et al, 1997). Loss of income due to disrupted employment of the infected family member is compounded by the very high cost of antiviral drugs. It is further compounded by the costs of funerals and the support of orphans and/or elders (Pitayanon, Kongsin & Janjareon (1994). In some areas, HIV/AIDS has become known as “grandmother’s burden”; HIV infected parents have died leaving the raising of orphans to grandparents (Seeley & Kajura, 1995).

**How Thai Women Cope with HIV/AIDS**

The psychosocial tasks which HIV/AIDS infected Thai women have to confront in order to manage their disease have been characterized in two Thai studies; unremarkably, the findings of these studies are similar.

The first study, by Nantachaipan (1996), characterizes these tasks as preserving dignity and prestige; seeking care and cure; maintaining health and well-being; maintaining self-esteem; developing skills in problem solving; coping with emotional or mental problems; keeping a sense of self-control; and, managing economic and daily living problems. In addition, HIV-infected people who participate in programs developed specifically to assist them in these tasks develop fewer symptoms and have a better quality of life than before entering into the program (Nantachaipan, 1996).
The second study, by Sangchart (1997), suggested that PWAs had to make the best of living with HIV/AIDS, i.e. "Thamchai", had to hide from others and had to integrate healing methods to cope effectively with their illness. "Thamjai" was achieved through six sub-strategies; accepting and retreating to live with HIV infection, paying karma, extending life, distracting, consulting and asking for help, and hoping to live longer. "Attempting to hide from others" involved two sub-strategies, hiding from oneself and from family and society. "Integrating healing methods" was undertaken to promote physical health, to prevent the spread of HIV, and to get relief from particular symptoms.

As is the case more generally (see above), strong spousal and financial relationships and access to HIV/AIDS Support Group are important in the amelioration of HIV/AIDS psychosocial implications for Thai women.

In one study of the experience of married couples with an HIV positive female spouse, Kongsuriyanavin (1997) reported that most women did not contract the virus from their current husbands. This study revealed that 17 of 24 couples live together in sympathy and understanding after the diagnosis of HIV infection. The husbands did not see their wives’ infection as related to promiscuity and the wives perceived their husbands to be sympathetic to and not repelled by them; their husbands were willing to offer support. Moreover, Wattanaphilin (1996) agrees that the spouse is an influential source of social support for participants with HIV infection.

Similarly, in other studies investigating family care-giving in HIV/AIDS infected families in Thailand, strong support, including financial support, was provided to HIV
infected people, primarily by wives, mothers or other close relatives (Jurawat, 1997). These caregivers lived in the same house and were able to understand and respond to the physical and financial needs and feelings of their infected family member (Charoenpatpasat, 1994; Chongsatitmun 1995).

How HIV/AIDS infected Thais cope with their disease apparently differs from PWAs in developed countries in (at least) one respect and that is the extent to which they rely on herbal medicines to ameliorate the complications of their disease. This is particularly true of northern Thais, including northern Thai women. For instance, Jundee (1997) noted that a range of herbal medicines was used to treat AIDS patients’ complications in the New Life Friends Center in Chiangmai province. She noted that for diarrhea, Psidium quajava linn was recommended, for anorexia or weight loss, Tinospora crispa was taken and, for fever, common cold, sore throat and tonsillitis, Andrographis paniculata Wall.ex Nees was used. Many PWAs feel physically better after taking herbal medicines. The New Life Friends Centre also emphasizes the psychological benefit of taking herbal medicines; they are thought to improve mood and emotional well-being (Shah, 1996).

**PWAs Groups in Northern Thailand**

PWA groups in upper northern Thailand, that is, in Chiangmai, Chiangrai, Phayao, Lamphun, and Lumpang have increased in number from one small group in 1994 to over 150 groups in 1997 (Natpratan, 1998). The first PWA group was established in Chiangmai following the arrest of a traditional healer who, in 1994, had made herbal medicine available to anyone infected with HIV. The healer was arrested by the Chiangmai Provincial Health Office and charged with public deception. Many of the
infected people who had taken herbal medicines, however, protested against the healer’s arrest and began sharing their problems and experiences. The protesters decided to form a group “The New Life Friends Centre”, the first PWA group in Chiangmai. This group worked in collaboration with both government and non-government agencies to develop the following guidelines (Natpratan, 1998).

1. **Health Care.** All members of PWA groups should be interested in their own health care. They often learn how to live with AIDS in good health not only from sharing experiences and ideas with other PWAs in the PWA Group but also from suggestions from experts in HIV/AIDS. PWAs should improve their health by:
   (i) taking herbal medicines. The herbal medicines taken by infected people should possess qualities both to relieve some symptoms and to promote health;
   (ii) receiving government funded health care services which are available at many community hospitals.

2. **Counseling Service.** Most HIV-infected people confront many psychosocial problems (see above). They require counseling services which provide psychosocial support and assist them to cope with their problems. The counselors may be the guardians or the members of the PWA Group who have been trained in counseling.

3. **Vocational Training and Marketing of Goods.** Some infected people elect to leave their employment because they fear their colleagues’ discrimination and some infected persons are dismissed from their jobs by employers. In
addition, some jobs become inappropriate for HIV/AIDS sufferers because of having to work too hard and in unsuitable working conditions. Loss of income can become a major problem for them. For these reasons vocational training or retraining is important. Most HIV infected people are both interested in and have the ability to engage in work such as embroidery, manufacture of dried and sandal flowers, and wreath arrangement. They should be retrained in these skills and develop markets for selling their products.

4. Home Visits. If a member of the PWA Group becomes too ill to attend the PWA Group, the group should visit her or him at home to provide basic health care. In addition, when a group member dies, other members should assist in preparing for the funeral.

5. Health Education for the Community. Those who have been trained for health care or counseling by government or non-government organizations, including the PWAs themselves, should provide health education as appropriate to their skills in their communities.

The PWA Groups in northern Thailand have developed enormously in the last few years in terms of both members and effectiveness. The current economic crisis in Thailand, however, has led to a decrease in government funding to support them. This means that the groups have to struggle to sustain themselves as supportive networks.
Summary

The pathogenesis of HIV infection is a function of CD4 T helper cell depletion and the lesions to which such immunodepletion give rise. The disease typically includes an acute initial infection, beginning 2-4 weeks following infection, an asymptomatic stage, which follows the acute infection and can last up to 10 years, a symptomatic stage and, terminally, end-stage disease. Clinical manifestations, which accompany each stage of the disease, are generally similar for women and men. They differ, however, in that women infrequently manifest Kaposi's sarcoma and they can also experience gynecological problems throughout their disease.

The psychosocial problems faced by HIV/AIDS infected people are due to the incurable, progressively debilitating and socially stigmatizing nature of the disease. Infected people are aware that they could become physically and cognitively impaired and socially isolated.

HIV/AIDS is an emotional roller coaster, it is a disease of profound loss. Infected people must come to terms with diminished self-concept, alternations to their abilities and relationships and to loss of future. Little wonder, then, that they variously respond to their disease with shock, denial, anger, depression, anxiety and suicidal ideation. These psychosocial responses in general are exacerbated in Thai women who, as kulasaatrii, wish to strive to continue to fulfil their caring and financial responsibilities to family.

In order to manage and cope with the psychosocial implications of their disease, HIV/AIDS infected people, including Thai women, require appropriate social support.
networks. Such networks critically include strong spousal and/or familial relationships to assist infected people to address the emotional and economic impact of the disease. They also include membership of a Person With AIDS Group where infected people can “just be themselves”, share problems and ideas and be trained to undertake employment appropriate to their health status.
Chapter Four

The Research Methodology

Introduction

As indicated in Chapter One of this thesis, the aim of this study was to discover how married or widowed women who have been infected with HIV/AIDS in rural northern Thailand deal with the many effects of HIV/AIDS on their lives. The problem was examined using the methods of grounded theory. This chapter, therefore, focuses on grounded theory methodology both in theory and, more particularly, on its practical application in this study.

The chapter begins with a theoretical introduction to symbolic interactionism, grounded theory’s generative theoretical framework and its relationship to grounded theory. Linkages between symbolic interactionism and grounded theory, which have previously been implicit, are made explicit. The discussion then turns to the history and background of grounded theory and the basis of the rift between Glaser and Strauss and Corbin is noted. The discussion then focuses on the different procedural recommendations recommended by Glaser and Strauss (1967), Strauss and Corbin (1990) and Glaser (1992) and examine these, as appropriate, in the context of data collection and analysis. The relevance of grounded theory to this study is made explicit and the apparent popularity of grounded theory among nurse researchers is discussed.

The chapter then focuses on the application of grounded theory in this study. It focuses on ethical considerations, data collection and data analysis.
The section on data collection includes literature review, interviewing and participant observation; the section on data analysis includes constant comparative analysis, theoretical sampling, theoretical sensitivity, coding and the role of memos and diagrams. The chapter terminates in a discussion of validity and reliability issues.

**Grounded Theory Methodology, In Theory**

**Symbolic Interactionism**

The theoretical basis for grounded theory is derived from the social psychological theory of symbolic interactionism (Benoliel, 1996; Chenitz & Swanson, 1986; Holloway & Wheeler, 1996; Morse & Field, 1996; Stern, 1994), which is a theory of human group life and human conduct (Blumer, 1969). Symbolic interactionism and its related research methods were developed at the University of Chicago School of Sociology between 1920-1950. Symbolic interactionism constituted a challenge to the “hegemony of functionalism” (Bowers, 1988; p.33).

Functionalism views the social world as a whole unit or system, which is composed of interrelating, functioning parts. Parts are generated and adapted based on their functional utility to the whole. Analysis of parts (e.g. individual roles, social groups, and organizations) is significant only in relation to their consequences for the whole. Individuals learn or internalize their functional expectations (roles) through socialization; they are determined, therefore, rather than determining (Merton, 1973).

Researchers in the functionalist tradition frame their studies on the functionalist theory of social life, i.e. they commence with a theoretical framework, posing their research
questions or problems in terms of the theoretical framework. These questions or problems are then converted into hypotheses and a study is designed to test these hypotheses (Blumer, 1969). Theories in the functionalist tradition, therefore, are hypothetico-deductively derived from grand theories, which are logically derived (what researchers are now pleased to term ‘armchair theorizing’).

Social interactionism, a “barbaric neologism” first coined by Blumer in 1937 (Blumer, 1969, p.1) differs substantially from functionalism in both theoretical perspective and research methods.

Symbolic interactionism is theoretically focused on the acting individual; the individual is regarded as determining rather than determined and society is constructed through the purposive interactions of individuals and groups. Its theories are empirically and (primarily) inductively derived. The central concepts of symbolic interactionism include the self, the world and social action (Charon, 1995).

The Self

The self is constructed through social interaction, firstly with ‘significant others’, i.e. those people directly responsible for the socialization of an individual, then others in wider social circles. Significant others are important in terms of self concept because of their “confirmatory and validitory” feedback on action/responses (de Laine, 1997). Through interaction with people more generally, the attitudes of the wider community are internalized (“as the generalized other”) and these interactions then function as an instrument of the self’s social control. Religious systems, the legal system and social norms are elements out of which the generalized other is constituted (de Laine, 1997).
Community attitudes are historical creations linked to contemporary situations; they are, therefore, subject to social change (de Laine, 1997). For instance, community attitudes to HIV infection change as the community’s HIV-related knowledge increases.

Self identity emerges in and through social interaction and is modified as definitions of self, the other, and the situations encountered, change (de Laine, 1997). The self is composed of two components, the “I” and the “Me” (Mead, 1934). The “I” is the active, dynamic interpreting component of the self; it is the reflector in that it interprets cues, synthesizes them with the other components of the self, relating them to those of the “Me” (Bowers, 1988).

The “Me” is the object of self-reflection, which can be defined to “myself” and others. It is the object of personal internal conversations and represents “my” self-image. Each individual has multiple “Me’s”, e.g. mother, PWA, daughter, seamstress. These multiple “Me’s” can exist simultaneously or consecutively and change over time. Who “I” am at any given time depends on the “Me” which is called forth by the context in which the “I” finds itself. (For example, when the child of a “Me” is diagnosed HIV positive, the salience of the “Me” that is mother becomes dominant.)

The World

The world in social interactionist theory refers to a world of symbols but this world is the ‘object world’ (Blumer, 1969). Not all objects are symbols; objects become symbols when meaning is assigned to them by the designator “I”. An object is anything which can be designated to the self and reflected upon i.e. physical objects (e.g. houses), social objects (e.g. families) and abstract objects (e.g. culture). Symbols,
which for the symbolic interactionist include both verbal and non-verbal behaviours, designate objects in the social world (Bowers, 1988). A common language provides people with a stock of ready-made linguistic symbols. Behaviours can be interpreted in relation to gestures, timing, facial and body movements and intonation.

What the above implies is that objects possess no inherent or intrinsic meaning; meaning is derived from how others act toward objects and these meanings are represented symbolically, in language. Such symbols indicate to others how particular individuals will act toward the object in question and allow them to adapt or adjust their own actions accordingly. Symbolic interaction refers to the social processes by which individuals are continuously designating symbols to each other and to themselves.

Participants in social life are continually attempting to determine how others are interpreting their actions in order to predict their responses and adapt/revise their own courses of action. Feedback from others indicates the relative accuracy of such assessments and whether or not the chosen course of action should be revised or maintained.

**Joint Action**

Joint action is accomplished, in particular social contexts, through a complex series of processes whereby participants fit their courses of appropriate action together (Blumer, 1969). It involves each participant attempting to take the role of the other to determine how objects are being designated (to enable prediction of behaviour), to select an appropriate action, verbal or non-verbal, and evaluate, from feedback, how the selected action is being interpreted by others (Bowers, 1988).
Joint action, i.e. meaningful human interaction, is always designed and conducted in complex, dynamic social contexts; to understand it, therefore, requires its observation and interpretation in those complex, social contexts.

Symbolic interactionism views meanings as social products, which are created through the defining activities of people as they interact. The meaning of objects for a person arises fundamentally out of the way they are defined to her or him by the people with whom s/he interacts.

Symbolic interactionists are insistent that social life must be studied through ‘first hand observation’ (Blumer, 1969, p.38) of the everyday lives of people in social spheres. Naturalistic enquiry is the only research mode through which to gain an understanding of subjects’ realities, i.e. of the objects designated as their designator understands them (Bowers, 1988).

“No theorizing, however ingenious, and no observance of scientific protocol, however meticulous, are substitutes for developing a familiarity with what is actually going on in the sphere of life under study” (Blumer, 1969, p.39).

Blumer (1969) asserts that the study of social life requires two processes, i.e. exploration (depiction) and inspection (analysis). Exploration is a flexible procedure, which enables the researcher herself to become familiar with the sphere of social life, which is the focus of the study. It also ensures that subsequent interpretations remain grounded in empirical reality. The line of inquiry, data collection and analyses all respond flexibly to what is to be found in the empirical data.
Inspection essentially refers to establishing the validity of the data analysis. The researcher conceptualizes the data and then carefully examines it for evidence of empirical instances of those conceptualizations.

**Symbolic Interactionism and Grounded Theory**

The theoretical framework of symbolic interactionism, as noted above, guides the principles of grounded theory (Benoliel, 1996, Strauss & Corbin, 1990) yet the specific links between them remain largely implicit. In this section, therefore, the researcher will attempt to make such linkages explicit.

According to Blumer (1969), the methodological stance of symbolic interactionism is that of direct examination of the empirical social world. This involves: confrontation (‘first hand observation’ – see above) with the empirical world which is accessible to observation and analysis; the raising of abstract problems regarding that world; the collection of data through disciplined examination of that world; the relating of categories derived from that data; the construction of hypotheses relating to such categories; the weaving of such propositions into a theoretical scheme; and, to test the categories, propositions and theory by renewed examination of the empirical world.


Another, more subtle point of association between symbolic interactionism and grounded theory relates to Blumer’s (1969) twin research components of exploration (depiction) and inspection (analysis); see above, this chapter.
Blumer’s exploration component, i.e. the component which enables the researcher to respond flexibly to what is found in her data, is clearly a function of purposive and theoretical sampling and constant comparative analysis. Indeed, it would be impossible to be flexibly responsive to what is to be found in data in the absence of constant comparative analysis and theoretical sampling.

Similarly, Blumer’s inspection component, i.e. the component where the researcher conceptualizes (theorizes) the data then checks those conceptualizations against the data, is strictly consistent with Glaser and Strauss’s (1967), Glaser’s (1978), Strauss’s (1987) and Strauss and Corbin’s (1990, 1998) views on the development and validation of analytic elements, i.e. codes, categories and theories.

**Grounded Theory**

**History and Background**

Grounded theory is a qualitative research approach that was collaboratively developed by sociologists Barney Glaser and Anselm Strauss, who worked together in very close cooperation although they came from different philosophical and research backgrounds (Glaser, 1992). Strauss came from the University of Chicago where there was a strong tradition in qualitative research and analysis (Glaser, 1992). Glaser came from a quantitative research tradition and trained at Columbia University (Glaser, 1992).

Glaser and Strauss developed the techniques for analyzing qualitative data that reflected their educational and philosophical backgrounds in research and analysis
(Glaser, 1992; Strauss & Corbin, 1990, 1998). The aim of the method is to develop a theory about social and psychological phenomena (Chenitz & Swanson, 1986). Its systematic techniques and procedures of analysis enable the researcher to develop either substantive or formal theory (Glaser & Strauss, 1967; Hutchinson, 1993); however, most grounded theory method has been used to develop substantive theory (Strauss & Corbin, 1994).

Substantive theory is developed from and for a substantive area of social inquiry (Glaser, 1978; Glaser & Strauss, 1967), for example, doing research into coping with cancer involves one particular situation and context. This theory has specificity and is limited in scope (Holloway & Wheeler, 1996). Formal theory, by contrast, is generated for a formal or conceptual area of sociological inquiry for example, stigma, socialization and social mobility (Glaser, 1978; Glaser & Strauss, 1967).

The thrust of Glaser’s (1992) critique of Strauss and Corbin is that the use of a preconceived coding paradigm ‘forces’ the data and risks the development of full conceptual description rather than a grounded theory. A detailed comparison of the original (“classical”) grounded theory method to Strauss and Corbin’s (1990) and Glaser’s (1992) is presented below, once grounded theory has been clearly defined.

Grounded Theory: A Definition

A grounded theory is one that is inductively derived from the study of social and psychological phenomena in which the objective is to develop a theory, generated from a highly systematic research process, that explains basic patterns of common interaction in particular contexts (Chenitz & Swanson, 1986; Strauss, 1987). The inductive method emphasizes data as the source for generating concepts and explanatory relationships. This approach, therefore, moves from the concrete and specific to the general and abstract.

When using this methodology, the concepts and relationships among them are not only generated, but they are also provisionally tested. It requires data collection, open coding, memoing, and determination of a core category, recycling of earlier steps in terms of the core category, sorting of memos and writing the theory (Morse & Field, 1996). It focuses on the discovery of concepts, the identification of core processes and the development of theory related to such processes.

Grounded Theory: Procedural Recommendations

As just indicated the appropriate procedures for developing a grounded theory have been the subject of acrimonious debate, particularly on the part of Glaser (1992). A
comparison of these procedural recommendations follows in Table 2. The debate, however, commences with the role and timing of the literature review in grounded theory and includes other scholars as well as Strauss and Corbin and Glaser.

The Role and Timing of the Literature Review

There are three apparently opposing views with respect to the timing and role of literature review in grounded theory. The first suggests that, at the beginning of a study, the literature should be reviewed to identify the scope, range, intent, and type of research that has been undertaken in the area (Chenitz, 1986), and to provide sensitizing concepts and an awareness of the gaps in knowledge before gathering data (Hutchinson, 1993). The literature review, both technical and non-technical, which may serve as primary data or to support ongoing analysis (Strauss & Corbin, 1990, 1998) continues as an ongoing process during data collection and analysis (Chenitz, 1986) to enhance theoretical sensitivity and guide theoretical sampling (Strauss & Corbin, 1990, 1998). What constitutes relevant literature may well change during the course of analysis as concepts emerge and become clearer. The literature can also provide secondary sources of data (Strauss & Corbin, 1990, 1998). After generating her/his substantive theory, the researcher should comprehensively review the literature to validate her/his theory (Strauss & Corbin, 1990, 1998).

The second and opposing view is held by Glaser (1992). He suggests that there is no requirement to review the literature prior to commencing a grounded theory study; indeed, he goes so far as to suggest that a literature review could lead to preconceived ideas. In his view, the literature should not be reviewed until the theory is emerging and is sufficiently grounded (Glaser, 1992).
This could be problematic in two respects. Firstly, as indicated, a literature review can demonstrate what has and has not been studied in any substantive area. Secondly, an ethics proposal requires sufficient review of the relevant literature to justify a study (Holloway & Wheeler, 1996). In light of this, Chenitz (1986) suggests a third approach, a compromise between the other two views; she suggests that researchers remain cautious with respect to a primary literature review.
Table 2 A comparison of the procedural recommendations for developing a grounded theory

<table>
<thead>
<tr>
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<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>(my addition)</td>
<td></td>
</tr>
<tr>
<td><strong>Sampling</strong></td>
<td>Theoretical sampling directed by emerging codes until categories are saturated.</td>
<td>Theoretical sampling: open, relational/ variations and discriminate.</td>
<td>Theoretical sampling: the process of data collection for emerging theory until each category is saturated.</td>
</tr>
<tr>
<td>Sources of theoretical sensitivity</td>
<td>Knowledge of coding families, conceptual ability and literature.</td>
<td>Professional experience, personal experience, literature and the analytic process.</td>
<td>The researcher’s knowledge, understanding and skill acquired by theoretical training.</td>
</tr>
</tbody>
</table>

Constant comparative data analysis

**Coding:**
- Open, theoretical and constant comparative coding.
- Choice from multiple coding families depending on best ‘fit’ to data.
- Primarily for sorting to form hypotheses.
- Movement over time with at least two stages – a basic social process.

**Focus on process:**
- Open, theoretical and constant comparative coding.
- Specified coding framework named the ‘Paradigm Model’.
- Code, theoretical and operational notes, diagrams, logic diagrams and integrative diagrams.
- Linking of action/interaction sequences or non-progressive movement.

**Memos:**
- Open, theoretical and constant comparative coding.
- Eighteen theoretical coding families.
- What works and fits the analysis.
- The theorizing and write-up of ideas as they emerge.
- Movement over time with at least two stages- a basic social process.
<table>
<thead>
<tr>
<th>Category development:</th>
<th>Relevant categories and relevant properties emerge by comparing incident to incident and/or to concepts looking for the relevance, the fit and emergent patterns until theoretical saturation occurs.</th>
<th>In terms of properties that are then dimensionalised and the categories grouped. Relationships validated against data. Gaps in categories are filled until theoretical saturation is reached.</th>
<th>Generating categories by comparing incident to incident and/or to concepts, naming a category by sociological constructs and in vivo words, developing categories in terms of properties and theoretically coding. The core category that accounts for a pattern of behavior which is relevant and problematic for those involved.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Core category emergence:</td>
<td>The basic social process emerges and is the core that accounts for most of the variation in the problematic pattern.</td>
<td>Explicating a story line about the central phenomenon around which other categories are integrated using the Paradigm Model.</td>
<td>Macro levels of analysis. What emerges?</td>
</tr>
<tr>
<td>Conditional/consequential matrix:</td>
<td>Nil – macro levels of analysis only.</td>
<td>Specified – moves between micro and macro levels of analysis.</td>
<td>---</td>
</tr>
</tbody>
</table>

Adapted from Annells (1997a, p.125)

Despite the apparent differences in procedural detail in these three modes, they have in common the basic techniques of grounded theory as initially described by Glaser and Strauss (Annells, 1997a, 1997b) that is, theoretical sampling; constant comparative data analysis; the need for theoretical sensitivity; memo writing; identification of core category; and, the ideals of 'theoretical saturation'.

**The Relevance of Grounded Theory to This Study**

Grounded theory is an appropriate research methodology to adopt for this study. Firstly, grounded theory is of use when little research has been undertaken in the subject area (Glaser & Strauss, 1967; Strauss & Corbin, 1998). Although there is now a huge research literature with respect to HIV/AIDS, there is little which focuses on
the impact of HIV/AIDS on women in developing countries and none which focuses specifically on the experiences of HIV/AIDS on married/widowed Thai women in the rural north. This study will be the first to do so.

Secondly, grounded theory methodology is particularly useful when ‘real-life’ situations require exploration (Glaser & Strauss, 1967). The researcher, through “first hand immersion” (Glaser & Glaser, 1967, p.226) learns to inductively understand and theorize about this world. It would be impossible to acquire an understanding of what HIV/AIDS infection means to rural Thai women, in terms both of its problems and how they learn to manage them (objects), without such a first hand or naturalistic immersion.

**Nursing Research Using Grounded Theory**

Since the 1960's nurses have investigated informant-context interactions in a wide variety of situations in nursing practice, nursing education and nursing administration. Indeed, interest in grounded theory method enabled Benoliel, in 1996, to analyze over 100 grounded theory articles written by nurses. Benoliel (1996) classified nurses’ interest and involvement both chronologically and in terms of substantive focus.

Chronologically, she identified four decades of research interest and involvement. These were the Decade of Discovery (1960-1970), the Decade of Development (1970-1980), the Decade of Diffusion (1980-1990) and the Decade of Diversification (1990-2000).
The substantive foci she identified were: family processes/adaptations; health seeking practices; infertility; individual adaptations in chronic illness; family processes in chronic illness; processes and practices of nurses; interventions and interactional processes of nurses; contextual/environmental influences; the illness experience; institutional/interactional processes and practices; passages and processes of vulnerable people; and, position papers on grounded theory.

Reasons have been suggested to account for the apparent popularity of grounded theory among nurse researchers. Cressler and Tomlinson (1988) suggest the method’s appeal is based upon the fact that the resultant theory arises from the actuality of the social processes under investigation and that there is no requirement to apply a pre-selected theory, quantitative measurement and statistical analysis. They further suggest that the method takes the nurse researcher into the world of nursing practice. In contrast, Christensen (1993) suggests a three-fold appeal. She cites the facilitation of theory development (when nursing has a dearth of theory), the provision of step-by-step processes for the novice researchers (of which there are many in nursing) and the freedom the method offers to produce a creative product.

Streubert and Carpenter (1995) also suggest that the development of nursing theory is one of grounded theory’s major advantages. They also suggest that the opportunity to work with researchers from other disciplines is a major benefit of the method.

The Application of Grounded Theory Methodology in This Study

The method of grounded theory which has been used in this study generally follows that described by Glaser & Strauss (1967) and Glaser (1978, 1992). There is one clear
exception, however, and it relates to the role and timing of the literature review. It will become clear, below, that the researcher chose to follow the advice of Chenitz (1986) and Strauss and Corbin (1990, 1998) rather than that of Glaser (1992).

The discussion will provide details of precisely what the researcher did and why (to ensure an adequate decision/audit trail) in relation to literature review, respondents, data sources, theoretical sampling, constant comparative analysis, memoing and diagramming, identification of basic social problem, identification of basic social processes and saturation; see Figure 1. These details, and those relating to analyses in Chapters Five and Six should demonstrate the trustworthiness of data collection and analysis in this study.

The discussion begins, however, by demonstrating the ethicality of the study.
Figure 1: Schematic Representation of the Grounded Theory Method
Ethical Considerations

In 1997, the research proposal was approved by the Human Ethics Review Committee (HERC) of the University of Western Sydney Nepean (UWSN) even though the data was to have been collected in Thailand. The researcher was residing in Australia, studying at UWS Nepean. It was also approved in northern Thailand, by the principal medical officer of the public hospital where most informants were recruited. The researcher sought to protect the rights of her human research subjects (Burns & Grove, 1997) of which, according to Wilson (1987), there are six: the right not to be harmed, the right to full disclosure, the right of self-determination, as well as the rights to privacy, anonymity, and confidentiality.

Since HIV/AIDS is perceived as a life threatening and stigmatizing illness (Crawford, 1996), infected women are potentially more vulnerable to emotional stress than people with other types of illness. The researcher was aware of this and took steps to address it. The researcher personally approached each potential respondent, explained the study fully to her and advised her of her right to withdraw from the study at any point. Informants were reminded of this right at the commencement of each interview. No participant either appeared to be or complained of being emotionally stressed during data collection. To the contrary, many respondents stated how much they appreciated the chance to speak of their experiences and feelings.

Consent was obtained through verbal agreement with all participants. Each gave verbal consent and it was clear from the conversation that they understood the purposes of the research and that they were free to withdraw at any time. In Thailand, consent is normally obtained verbally, not in writing. Loue (1995) states that in
developing countries it may be impractical to invite written consent from largely illiterate populations. In Thailand it is culturally appropriate to accept the spoken word (Songwathana, 1998) and, as a result, it was acceptable to require verbal consent only following a full explanation of the research.

To protect confidentiality, all data for this study were collected solely by the researcher and pseudonyms were used for all participants. Only the researcher had access to the list of respondents' names and addresses and their pseudonyms; this list was kept in a locked drawer, separate from audio-tapes and transcripts. No real names have been used nor will they be included in any publications or reports of this study. The participants were assured that the information they provided for the researcher would be treated with absolute confidentiality. The recorded interviews and field notes were preserved in a safe locked location and only the researcher had access to these records. These data will be destroyed as soon as this study and its evaluation process are complete, or not later than five years, to allow for a number of articles to be written for publication.

The Literature Review

In the early stages of this research, the researcher reviewed the literature on grounded theory methodology. She also reviewed the HIV/AIDS literature to ascertain that her planned area of research had not been adequately researched before. During data collection and analysis, literature, which related to women with HIV/AIDS in developed and developing countries, particularly Thailand, was comprehensively reviewed. Appropriate reference to pertinent literature concerned with Buddhism, folklore and village culture assisted the researcher to validate the emerging theory.
The Research Setting

This research was conducted in rural northern Thailand where HIV infection is highest (see Chapter One). Chiangmai province is the largest metropolitan area in northern Thailand, located 750 kilometers north of the capital, Bangkok and is the most important centre of the north, economically, politically, socially and culturally (Wijngaarden, 1995). Chiangmai was selected as the most appropriate research venue because this city has the highest rate of infection among women in Thailand (Cash, Anasuchatkul & Busayawong, 1995) which implies that the AIDS crisis in this province is more devastating than in other provinces. In addition, the researcher is a lecturer in the Faculty of Nursing, Chiangmai University, and has served on a number of the committees evaluating Care International/Thailand's Living with AIDS project from 1993 to 1995.

As previously indicated (Chapter One, above) the Living with AIDS project was conducted in Chiangmai, Chiangrai, and Prayao provinces in upper northern Thailand. One of the findings was that married women with HIV/AIDS seem to remain relatively healthy compared to their husbands most of whom had died from opportunistic infection. Yet a computerized literature search failed to reveal any studies that explored, in depth, how HIV/AIDS affects women in Chiangmai.

The researcher chose one sub-district about thirty kilometers away from Chiangmai, for a number of reasons. First, the site provided an opportunity to recruit participants from among the infected women who were members of a Persons With AIDS (PWA) Group. Second, this area consists of rural villages close to the city where villagers are
mainly farmers. Third, there was an active leader of the PWA group who was very cooperative and, finally, the participants were willing to share their experiences. In addition, and at the suggestion of a nurse from a sub-district hospital, another district was selected with additional informants to provide further data and possibly a different perspective. The decision to include respondents from a second district can be considered in terms of both theoretical sampling and determination of saturation. Data was collected between February 1998 and August 2000 until the researcher and her supervisors were convinced saturation had been achieved.

**Study Informants**

A purposive sample of Thai women with HIV/AIDS in this rural area was obtained, as "one who has the knowledge and experience the researcher requires, has the ability to reflect, is articulate, has the time to be interviewed, and is willing to participate in the study" (Morse, 1994, p.228). All these women were married and/or widowed. After the local hospital board had approved the project, the chief doctor introduced the researcher to the hospital’s AIDS liaison nurse. The researcher then explained the research process and study objectives to that nurse who then conveyed this information to potential informants.

A group meeting of women infected with HIV was held once a month at this hospital. This provided a good opportunity for the researcher to meet members of the group. The liaison nurse introduced the researcher to the members of the group and facilitated an invitation to participate. The informal interactions, which occurred with participants, were also very helpful in familiarizing the researcher with them at this stage.
All of the members were willing to participate. Some participants invited the researcher to visit them at home and some also gave consent for the researcher to visit friends who belonged to the group, but who were absent from the meeting on this occasion. The liaison nurse arranged to drive the researcher to informants' homes for interviews.

Visiting their homes allowed for data from observation to be included in the study. In particular, it provided some insight into the village context in which informants lived, and in gauging the type of family support available to them.

In all, there were 24 participants including those with both symptomatic and asymptomatic disease. During the course of this research six of the twenty-four participants died from opportunistic infections or other complications. At the time of writing, among the rest of these participants, some have shown symptoms and some remain asymptomatic. Seven of the seventeen remaining participants have remarried. The age of the participants ranged from 20 to 45 years. All the participants were Buddhist. The general characteristics of these participants are illustrated in Table 3, below.
Table 3  Demographic characteristics of all participants at commencement of study

<table>
<thead>
<tr>
<th>Sample characteristics</th>
<th>Total Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>20-29</td>
<td>10</td>
</tr>
<tr>
<td>30-39</td>
<td>10</td>
</tr>
<tr>
<td>40-45</td>
<td>04</td>
</tr>
<tr>
<td>Religion</td>
<td></td>
</tr>
<tr>
<td>Buddhist</td>
<td>24</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Primary School</td>
<td>20</td>
</tr>
<tr>
<td>Secondary School</td>
<td>03</td>
</tr>
<tr>
<td>High School</td>
<td>01</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>00</td>
</tr>
<tr>
<td>Married</td>
<td>09</td>
</tr>
<tr>
<td>Widow</td>
<td>15</td>
</tr>
<tr>
<td>Occupation</td>
<td></td>
</tr>
<tr>
<td>Manual labour</td>
<td>05</td>
</tr>
<tr>
<td>Farming work</td>
<td>04</td>
</tr>
<tr>
<td>House wife</td>
<td>02</td>
</tr>
<tr>
<td>Sewing</td>
<td>08</td>
</tr>
<tr>
<td>Employee of HIV/AIDS support</td>
<td>05</td>
</tr>
<tr>
<td>Foundation</td>
<td></td>
</tr>
<tr>
<td>Income (Baht/month)</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>03</td>
</tr>
<tr>
<td>&lt;1000</td>
<td>06</td>
</tr>
<tr>
<td>1000-2000</td>
<td>04</td>
</tr>
<tr>
<td>2001-3000</td>
<td>04</td>
</tr>
<tr>
<td>3000-5000</td>
<td>07</td>
</tr>
<tr>
<td>Mode of transmission</td>
<td></td>
</tr>
<tr>
<td>Sexual, from HIV-infected</td>
<td>24</td>
</tr>
<tr>
<td>husband</td>
<td></td>
</tr>
</tbody>
</table>

Theoretical Sampling

When this research began, the researcher purposively sampled individuals who could provide the most information about the topic under study. In the early period of collecting data, the researcher interviewed three participants and then coded all the data, which the researcher analyzed with respect to the various themes, which had begun to emerge. New themes and relevant areas of inquiry were identified from the first three interviews. As the study progressed, the researcher found the next
participants and continued collecting data. The objective of this approach was to look for variation, and to seek data that could shed more light on developing themes, or that indicated additional properties of categories or processes. The researcher decided what data to collect next and where to seek them in order to generate her theory (Glaser & Strauss, 1967).

**Data collection: In-Depth Interview**

As indicated above, in-depth interviews were the primary means of collecting data in this study. In-depth interviewing involves taking an unstructured or semi-structured approach (Minichiello, Aroni, Timewell & Alexander, 1995) where conversations are informal (Minichiello, Madison, Hays, Courtney & St John, 1999). Normally, training in in-depth interviews is necessary; however, as the researcher had previous experience of this interviewing technique in an earlier qualitative study in which she had been involved, she required only some advice on open-ended questions and a brief review of interview strategies from her supervisor. Background data (e.g. demographics) were collected for each informant during the first interview.

Each interview took place either in the participants’ homes, when invited, or in a private, quiet room at the local hospital. Timing depended on the wishes of informants. The researcher was at pains at the commencement of each interview to establish or re-establish rapport and trust (Minichiello et al, 1999; Nieswiadomy, 1998), and to assist the informant to relax and feel comfortable. When she was satisfied that this had been achieved, she reminded informants of their right to withdraw from the study and invited them to reconfirm their willingness to participate. When consent had been reconfirmed, the interview commenced.
All interviews were informed by guidelines (Stern, 1985). The first interview always commenced with the researcher stating the purpose of the research and then asking informants a general question such as “I know you have been diagnosed with HIV/AIDS, would you like to tell me what it’s like living with HIV?” If the participant looked ill or tired, however, she would simply be asked how she was feeling today.

The researcher attempted to keep the interviews as free-flowing and informal as possible; however, the interview guide ensured that all the areas she wished to explore with informants were, in fact, covered. At the first interview this included: how informants discovered they were HIV-infected and their reactions; how the disease affected their lives and relationships and their reactions: and, how do informants cope with and manage their disease and its implications (see Appendix One).

Second and subsequent interviews were guided by analyses of the first or previous interview; guidelines were constructed to clarify and elaborate on previous interview data, to test emergent theoretical constructions and address “gaps” in data (Glaser, 1978; Strauss & Corbin, 1990). One example of this was when the researcher conducted two extra interviews to explore the reasons why these women stayed with and cared for the husbands who had infected them with HIV/AIDS.

During each interview, the researcher tried to encourage participants to speak freely and candidly. She encouraged them verbally, “tell me more”, “how do you feel about that?”, “I see..”, “hm...mm...”, “..yes, I see...”. She used probing questions and echo technique to elicit more in-depth information. At all times, however, because of krenge
Jai, she avoided questions or words which could distress or offend participants. At times, this might have limited both the amount and quality of data collected.

The number of interviews conducted with each participant varied from one to four; however, most participants were interviewed at least twice (Foddy, 1993), with the two interviews three to six weeks apart. Re-interviewing allowed the verification, clarification and elaboration of information obtained at first interview or to cross-check information acquired from other sources.

The initial interview took approximately 30 minutes to one hour. The subsequent interviews lasted 20 to 30 minutes. However, the researcher actually spent approximately one and a half to two hours with each participant per interview to establish trust and rapport. With the permission of all participants, each interview was audio-tape recorded to confirm the data; the interview tapes were then transcribed as soon as possible. In addition, short field notes in the form of a short note, a key word or a few phrases were written up as soon as possible following interviews.

To avoid researcher fatigue, no more than two interviews were conducted on any one-day. A total of sixty-two interviews were conducted. All were conducted in Thai, transcribed in Thai and analyzed using Thai Ethnograph (see below). The researcher undertook data entry herself; it was very arduous and time-consuming. In addition, because her supervisor was in Australia, the researcher was required to translate six entire interviews as well as components of others to assure her supervisor that her data collection and analytic techniques were satisfactory and adequate.
The researcher dispatched the complete transcript of her first interview to her supervisor in Australia for feedback; this suggested that the researcher incorporate more open-ended questions into the interviews. Advice on how to do this was also provided. Feedback was given on a further nineteen interview transcripts, six in their entirety, prior to the researcher’s return to Australia.

Following a period of further data analysis in Australia, the researcher returned to Thailand for further data collection. It had been noted that some of the data harvested during the initial data collection period did not appear to be quite as rich as it could be. It was thought by the researcher and her supervisors that this could be due to either the conceptual simplicity of her informants and/or the researcher’s inappropriate interviewing technique. It was very difficult to ascertain from the transcripts which was causal; as highlighted in Chapter One, strictly accurate translation from Thai to English can be difficult due to language differences.

The researcher was carefully prepared for her second episode of data collection. Her supervisors schooled her very intensively on her interview technique, requiring her to practice her interviewing skills on them. Instruction was given on how to facilitate informants sharing of in-depth information.

It was also noted during analysis of the first interviews that a number of informants nursed their infected husbands through terminal illness, despite having been infected by them. The researcher was advised to ask such women whether they did this out of *kreng jai* (because they were *kulasatrii*) or out of genuine love.
Data Collection: Participant Observation

When invited to do so, the researcher undertook participant observation whilst interviewing respondents in their own homes. During these visits, the researcher noted the home environment, its cleanliness, comfort and evidence of affluence or poverty. She also noted evidence of respondents’ sociability, for example, if water was available at the door for visitors.

In addition, because Thais live in very close proximity to each other, without fencing between dwellings, the researcher sought to witness interactions between respondents, their families and their neighbours.

Field notes were kept of such observations (Russell, 1999) and these helped to inform data analysis.

Using the Constant Comparative Method

The constant comparative method of analysis was used in this study until a dominant basic social process emerged. It involved coding the data for categories, comparing incidents applicable to each category, integrating categories and their properties, establishing links between categories, identifying the core process, relating all categories to the core process, delimiting the theory and writing the theory. Coding and analytic procedures were facilitated by the concurrent writing of memos and diagramming of ideas about the categories and their relationships. (Theoretical sampling was ongoing as further data were sought from a variety of sources, including literature, to elaborate and verify categories and their properties.)
Through the constant comparative method, comparing incidents applicable to each category and integrating the categories and their properties (how the categories are defined, the conditions that explain why and when they occur, the strategies interactors use and their consequences) resulted in the elevation of data to more abstract levels. This involved developing theoretical constructs and their relationships by linking substantive categories (reflections of the substance of what was said or observed) and their properties and developing theoretical categories. Theoretical codes conceptualized how substantive codes related to each other as hypotheses to be integrated into the theory (Glaser, 1978, p. 55).

**Coding Procedures**

Audio-taped interviews were transcribed verbatim and then entered into the Thai Ethnograph software program. Field notes from home visits were treated in the same way. These data were printed with wide right hand margins and each line was numbered. Printouts were used for coding of categories which reflected the meanings of what was happening in the data.

Each transcript was read carefully and key words were noted as well as phrases to indicate incidents, events and facts. A hiliter pen facilitated this. The data were conceptualized by identifying and naming concepts that reflected each discrete incident, event, etc. and writing these codes in the left hand margin adjacent to the transcription. To ensure consistency of coding, continuous comparison of incident with incident was undertaken.
These concepts were then compared against each other and those that appeared to relate to the same phenomenon were clustered under a more inclusive and abstract concept, a category. The phenomenon represented by each category was given a name that was more abstract than that given to the concepts clustered under it. Some codes were found to be attributes or characteristics (properties) of higher level categories. Properties of categories were identified and these were noted in memos and were clarified and densified through ongoing data collection and analysis. Memos were linked to the data representing the category by transcript page and line number.

**Open Coding**

Opening coding, that is, coding for as many categories (abstractions of the phenomena observed in the data) was commenced immediately after transcription of the first interview. Although open coding is normally typified by the multiple coding of individual phrases, lines or sentences (events, incidents etc.), in this study the data generally did not warrant this (see below). Coding was relatively straightforward due to the apparent simplicity of participants’ verbalizations.

Each data segment was coded and the code entered on the left-hand margin opposite the transcribed interview. This process was accompanied by the writing of memos in a separate notebook, noting date, interview number as well as the line number and the code to which the memo related. As each new code was generated, the code name and its definition were noted on computer file.

Open coding began using *in vivo* (Glaser, 1978; Glaser, 1998; Strauss & Corbin, 1990) or substantive codes. For instance, the following (translated) transcript excerpt shows
both the in vivo codes generated by the researcher and those she generated from the substance of the data.

Informant 11: Transcript Excerpt

At the time I dared not tell my husband. I didn’t want to shock him. He might have wanted to commit suicide. I know his personality. He’s sensitive. I hide all my feelings. When he got sick he asked me if he was HIV positive. I lied that he only had pneumonia. He asked if I had lied to him. I said that he only had pneumonia really. I tried to distract him by asking him out, trying to console him. I tried to tell him to look after his health. He is a heavy smoker and never listens to my warning.

Theoretical Coding

Theoretical codes conceptualize how substantive codes and categories relate to each other as hypotheses to be integrated into a theory (Glaser, 1978, p. 72). The researcher labeled (coded) these behaviours as ‘protecting husband’. The following example illustrates substantive coding and theoretical coding.

<table>
<thead>
<tr>
<th>Substantive Coding</th>
<th>Theoretical Coding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear of telling husband</td>
<td>Protecting husband</td>
</tr>
<tr>
<td>Fear of shocking husband</td>
<td></td>
</tr>
<tr>
<td>Fear of his wanting to commit suicide</td>
<td></td>
</tr>
<tr>
<td>Knew husband enough to hide own feelings</td>
<td></td>
</tr>
</tbody>
</table>

The construction of theoretical codes was facilitated by asking questions of the data such as ‘what is this data a study of?’ ‘what category does this incident indicate?’ and ‘what is actually happening in the data?’ (Glaser, 1978, p. 55). This led to the identification of antecedent conditions, interactions, strategies and their consequences and the formation of categories. Each incident was then compared to other incidents
and then the categories were compared to each other to ensure that they were mutually exclusive and covered the behavioural variations.

For instance, it became obvious that participants did not only protect their husbands; the data demonstrated that they protected the ‘family unit’ (that is, wife, husband and, where relevant, children) as a unit, they protected themselves and they protected their children. It also became obvious that the protective strategies that they employed were designed to protect these people from actual or expected social discriminatory behaviour from others in their social networks. They variously told lies, concealed AIDS-related lesions and changed employment and social activities; clearly, they were trying to hide their diagnoses. However, close proximity to others, and the likelihood of others recognizing that they had HIV/AIDS, made it difficult to conceal. In addition, the participants’ home villages, the PWA Groups they frequented, the distant schools to which children were sent were conceptualized as “hide-outs”, that is, as places that were relatively safe. (A ‘hide-out’ can be discovered....) Limiting their activities in the village (e.g. not cooking at funerals) and changing their jobs were also conceptualized as ‘hide-outs’. Thus, the major category, conceptualized as a gerund, “Hiding Out With HIV/AIDS” was constructed.

Neither Glaser’s (1978) families of theoretical codes nor Strauss and Corbin’s (1990) coding paradigm were deliberately used by the researcher. Level two and three theoretical codes (or, axial and selective codes) emerged during analysis sessions with the researcher’s Ph.D. student peers and supervisors. Each participant in this group, including the researcher, was required to tell ‘the story’ of the data, identifying both common incidents, experiences etc. and, where relevant, exceptions /outliners. Stories
were not dissimilar to the narrative in the preceding paragraph; however, they were, of necessity, much more detailed.

Energetic discussion always accompanied such story-telling and, where tentative theoretical codes indicated, careful re-examination of the data. For example, the researcher re-examined the data three times following group discussion of the category ‘hanging in’. Firstly, the group suggested that ‘hiding out’ could be a subcategory of ‘hanging in’ and, secondly, the group initially wanted to construct the behaviours and processes characteristic of ‘hanging in’ as more heroic than stoic. Eventually, she (and her colleagues) was satisfied with the validity of ‘hanging in’; informants frequently stated that, for range of reasons, they had resolved to “fight for their lives”. In addition, the data demonstrated that participants could not ‘hang in’ and ‘hide out’ simultaneously; they were discrete and mutually exclusive categories.

Through this process of analysis and validation, the categories were elevated to more abstract levels, linkages between categories were identified and relationships between categories were integrated. Categories were collapsed and identified as properties or subcategories of higher order categories until three level 3 theoretical codes were identified.

**Identifying the Basic Social Problem**

Analysis was directed towards discovering the basic problem experienced by informants in this study. The basic social-psychological problem shared by informants was ‘surviving with HIV/AIDS’ (in rural northern Thailand); they had to confront a range of physical, psychosocial and economic problems to survive with their disease
(they were unlikely to survive their disease). These problems resulted directly from the pathophysiological consequences of the disease and, more particularly, from the cultural constructions of the disease, including participants' own, in rural northern Thailand.

**Identifying the Basic Social Processes**

Having identified the basic problem confronting informants in this study, analysis was then directed to discovering how the problem was managed in this particular context. Two complementary categories were identified. These were ‘Hanging In With HIV/AIDS’ and ‘Hiding Out With HIV/AIDS’. These categories account for all the variation in the data.

**Saturation**

Coding continued until saturation had occurred, that is, all levels of codes appeared complete with no new conceptual information available to indicate new codes or the expansion /elaboration of existing codes. No new data could be found to develop new categories, or properties of categories, as they related to the core processes and all linkages between categories were clearly established.

Interestingly, both the researcher, her peers and supervisors felt a sense of closure at saturation.
Memo Writing and Diagramming

Writing memos and diagramming involved the theorizing about codes and their relationships; they were written during analysis (Glaser, 1978). Both facilitated the elevation of data to higher levels of conceptualization; they also assisted in the development of categorical properties and hypotheses about linkages between categories and/or properties (Wilson, 1989).

The researcher asked questions of the data in memos; sometimes these were accompanied by tentative answers. In addition, suggestions / recommendations for further data collection were noted together with further sources of information it might be useful to pursue.

The following is an example of a theoretical memo written on 10 February, 1999; it refers to four participants who protected their husbands from learning that they were HIV/AIDS infected and that they had infected their wives:

There was one group of four women whose responses to finding that they had HIV contracted from their husbands was markedly different from the other women informants.

Even though HIV had been transmitted from their spouse, four participants were afraid of their husbands discovering the truth that they were infected with HIV. They were afraid that their husbands would feel sad. Their response was to protect their husbands.

Contraction of HIV from husband:
Husband was not aware of having HIV. Men did not associate HIV information (newspapers, posters, TV) with themselves as likely to be infected. Because of this they did not take precautions. They did not worry about any consequences of having unprotected sex with a prostitute. (note: To explain this matter find the information or research in terms of low use of condoms).

Protecting their husbands:
The women lie to their husbands, telling them that they had other sicknesses. They also encourage their husbands to look after themselves. They protect their husbands. Why were they protecting their husbands? (note: can this be explained in terms of culture, philosophy of Buddhism and role of wife in rural northern Thailand:)

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In terms of the philosophy of Buddhism, they believe in the law of karma. Traditionally, wives have to take care of their families. They try to carry on whatever happens in their families. They also perceive themselves as unequal within their marriages and themselves as powerless. Male dominance within Thai rural culture can be explained in terms of ingrained traditions and perceptions, despite a veneer of modernity: TV, motorbikes, kitchen and other appliances.

As this memo demonstrates, memo-writing directed the researcher’s further theoretical sampling and enhanced her theoretical sensitivity (Strauss & Corbin, 1990).

Diagramming was used extensively, particularly during group analysis seminars. It enabled the rapid schematization of codes and their possible relationships. Some were relatively simple, for example, those focusing on level 1 and 2 codes:

Lesions
Mouth ulcers
Diarrhea
Weight loss
Allergy to sunlight
Anorexia
Fatigue

physical manifestations of HIV/AIDS
Others were rather more complex, focusing mainly on level 2 codes:

Lying to husband
Advising husband
Caring for husband

Lying about child
Taking to distant school

Lying about own diagnosis
Limiting social activities
Concealing lesions
Changing jobs

Both lying about diagnosis
Both changing jobs
PWA Group, home village, distant school

protecting husband
protecting child
protecting herself
protecting family unit

Trying to Hide From AIDS-Related Discriminatory Behaviour
Hiding out with HIV/AIDS

“Hide Out”
Yet others represented antecedent conditions, results, consequences and strategies:

**Economic Implications of HIV/AIDS**

- Diagnosis HIV+
- Discovery of HIV+ diagnosis (employers screen program; accidental)
- Loss of financial security
- Loss of home
  - Loss of role/self esteem
  - Inability to purchase food
  - Inability to purchase medications
  - Inability to pay for children's education
  - Loss of social outlet
- Fear of discovery of HIV diagnosis
- Return to village/mother
  - Search for suitable employment
  - Accept financial assistance
  - Accept food from family
  - Accept emotional support from family
- Fatigue
- Weakness
- Weight loss
- Appearance of skin lesions

**The Ethnograph-A Computer Software Program**

In this study, the typed transcripts of interviews were used with the Ethnograph software program (Seidel, Friese & Leonard, 1995), enlisted to assist in data analysis and management. It enabled the storage of large amounts of textual data that had been coded line by line, with the flexibility to change or recode data during the analysis stage (O’ Connell, 1997). In addition, Ethnograph also allowed the researcher to search for codes and sort the data files into analytic categories. In the transcriptions, coded segments of data were overlapping and nested within other
codes; Ethnograph enabled the researcher to retrieve these across all data files as single or as multiple codes (Irurita, 1996).

The Thai transcriptions were numbered into the text line and were coded in English. The initial coding was performed manually on the print out of the data files using the principles of substantive and theoretical coding (see page 115).

The codes were written on the printed interviews and the line numbers were marked to indicate the segments of data, which illustrated where some codes of data overlapped or nested with other codes and some were independently coded. These processes are termed “code mapping” (Seidel, Friese & Leonard, 1995). After code mapping the codes were entered into the Ethnograph computer program. During this process, codes were modified or changed, added or deleted, as the researcher required.

Ethnograph in a qualitative study is useful in order to analyze the large amount of textual data. However, in terms of the ‘grounded’ analytical approach, the computer program cannot assist with the creativity and intuitive nature of qualitative research (Stroh, 2000). For this reason, the researcher also analyzed the data manually, after using the Ethnograph program, to confirm the credibility of the emergent categories in this study.

**Credibility, Transferability, Dependability and Confirmability**

From the beginning of this study the researcher has worked assiduously to ensure that it has been rigorous throughout. In addition, she reviewed the grounded theory
literature very thoroughly before commencing the study to ensure she was familiar with its methodology and purposes. As a result, and as this chapter bears witness, the procedural requirements of grounded theory method have been faithfully followed. There are, however, a number of processes and procedures which the researcher wishes to emphasize; these relate to activities undertaken prior to data collection, during analysis and following analysis.

Firstly, each interview was conducted with the aid of guidelines. The initial interview guidelines identified topics to be covered and each subsequent interview was informed by analysis of its predecessor. Memos were written as appropriate. Secondly, the researcher listened carefully to recorded interviews, and noted any variances in tone, etc. (O'Connell, 1997). The audio-tapes were then transcribed as soon as possible, by the researcher, who then checked that the transcriptions were an accurate record of the interviews. Transcripts were then given to participants who confirmed their contents (Brink, 1991).

Thirdly, as well as receiving feedback from her supervisor on her first interview, the researcher also sought feedback from three colleagues in Thailand who were fluent in English and familiar with qualitative research. These colleagues were given transcripts of the first three interviews and their preliminary analyses. All three agreed that coding appeared valid.

Fourthly, the study incorporated group analysis to reduce researcher bias and enhance analytic validity. As discussed above, these group sessions assisted in verifying coding and categories; this increased the credibility of the emergent categories (Sandelowski, 1986, 1993).
Fifthly, the researcher undertook ‘member checks’ of her substantive theory (Denzin & Lincoln, 1994). She returned to the study sites and discussed her theory with the HIV/AIDS liaison nurse and six participants. In addition, the researcher presented her theory to the PWA Group in Chiangmai in August 2000; she explained her categories of ‘hanging in’ and ‘hiding out’ to group members, in Thai. They confirmed that these categories fit their experience.

Sixthly, and as also discussed above, the researcher sought to enrich her data by undertaking two additional interviews in August 2000. These interviews involved participants who were “better educated” (i.e. they had had more years of general education) than earlier participants and were conducted following intensive practice in in-depth interviewing with the researcher’s supervisors. Despite these considerations, however, no further data was elicited from them.

Summary

Grounded theory, a qualitative research methodology, was “discovered” (invented, developed) by Glaser and Strauss (1967) and further elaborated by Strauss (1987), Strauss and Corbin (1990,1998) and Glaser (1978, 1992, 1994, 1998). In his 1992 text, Glaser vehemently criticizes Strauss (Glaser never mentions Corbin) for his 1990 “recipe” text which leads only to full conceptual description rather than grounded theory. Strauss and Corbin and Glaser differ in a number of procedural details; their main differences, however, lie in their views on the role and timing of the literature review and coding techniques. Glaser’s position is that a previous literature review can bias the analyst, as can the use of a coding paradigm in analysis.
Data collection in grounded theory typically includes interviews (usually semi-structured), participant observation and document analysis; these methods enable the rich description of social contexts and an understanding of interactors' meanings and their inter-relationships. These contextually-dependant meanings and their interrelationships are then theorized.

Data collection in grounded theory is purposive and driven by emergent theory; it is considered complete when categories are saturated, that is, when further data collection harvests no new information.

Data analysis, that is, the identification of codes and categories and their relationships commences immediately following (if not during) the first data collecting episode. Analysis continues concurrently with data collection throughout the study using constant comparative method, memos and diagrams. Constant comparative analysis, memos and diagrams enhance theoretical sensitivity.

Symbolic interactionism is grounded theory’s generative theoretical framework. Blumer’s (1969) concepts of exploration (depiction) and inspection (analysis) are strictly consistent with Strauss and Corbin’s and Glaser’s views on constant comparative analysis, theoretical sampling and the development and validation of theory.

Grounded theory is an appropriate methodology with which to explore the experiences of rural married/widowed women in northern Thailand who are infected
with HIV/AIDS. Firstly, there have been no previous studies which have explored these particular experiences. Secondly, first hand immersion in the social world of these women is prerequisite to the inductive understanding and conceptualization of these experiences.

Grounded theory methodology is apparently popular among nurse researchers. This may be due to the method's ability to generate nursing theory, its provision of a procedural prescription and the freedom it allows to produce a creative product.

In terms of the practical application of grounded theory method, the rights of the participants were carefully protected throughout the course of this study; no participant complained of being stressed during data collection, no participant withdrew and a number expressed their appreciation for the opportunity afforded them by the study to speak of their experiences and feelings. Verbal consent only, as is the norm in Thailand, was secured from each participant prior to data collection.

The study involved a purposive sample of 24 HIV/AIDS infected married or widowed Thai women from Chiangmai Province. Data collection consisted in in-depth interviewing and participant observation in informants' homes. A total of 62 interviews were conducted. Each interview was informed by guidelines, audio-taped and transcribed verbatim (in Thai) by the researcher herself. The researcher also undertook all data entry into Thai Ethnograph software. Six complete transcripts were translated into English, as well as relevant sections from the remainder, to convince her supervisors and grounded theory peer group that her analysis was adequate and accurate.
Data was analyzed using the constant comparative method and analysis and theoretical sampling were facilitated by memoing and diagramming. Analysis was further facilitated by grounded theory peer group discussion. Data collection and analysis continued until the researcher, her supervisors and her peer group were satisfied that saturation had been achieved.

The basic social problem experienced by participants was “Surviving With HIV/AIDS” which subsumed a range of physical, psycho-emotional, socio-cultural and economic problems. These problems resulted directly from the pathophysiological consequences of the disease but, more particularly, from the social constructions of HIV/AIDS in rural, northern Thailand. The basic social processes through which participants managed to survive with HIV/AIDS were distinct but complementary; these were identified as “Hanging In With HIV/AIDS” and “Hiding Out With HIV/AIDS”.
Chapter Five

Findings: Surviving With HIV/AIDS

Introduction

The overall aim of this study was to discover and theorize the experiences of HIV/AIDS of married or widowed women in the north of Thailand and how they coped with or managed their infections in the culture-bound contexts of rural villages. The dominant (or, basic social) problem which emerged as the core category was labeled “Surviving With HIV/AIDS”. These women had to survive with HIV/AIDS; they were and, to the present time remain, unable to survive HIV/AIDS. They were unable to look beyond relatively short-term survival. Six informants have already succumbed. The data reveal a number of inter-related issues which render surviving with HIV/AIDS problematic. Some of these are due to the clinical manifestations of the disease, which affect the women’s ability to undertake the normal activities associated with their role and status as women, i.e. as kulasatrii. The majority, however, which also affect their ability to undertake the normal activities associated with their role and status as women are directly or indirectly attributable to the socio-cultural meanings (designations) associated with HIV/AIDS in northern Thailand. What this implies, rather obviously, is that HIV positive women in the rural north of Thailand would not experience this group of problems at all if their parent culture did not construe (designate) HIV/AIDS in the way that it does.
Surviving With HIV/AIDS

"Surviving with HIV/AIDS" for these rural, northern Thai women was a complex and fluctuating phenomenon, which varied in dimensions. More specifically, it was a psychologico-motivational approach or orientation to their disease which developed in response to a number of issues and problems, which collectively impeded their ability to carry out their normal social role activities. This orientation had its roots in the women's interpretation of familiar symbols (gestures, words and behaviours of others in their villages) and their understanding of these through the perspective of the generalized other, derived from their enculturation.

Data analysis revealed that participants confronted four distinct types of problem, categorized as "The Physical Implications of HIV/AIDS Infection", i.e. problems resulting from the pathophysiology of the disease, "The Psycho-Emotional Implications of HIV/AIDS Infection", i.e. "internal" beliefs and feelings, emotional responses, etc., "The Economic Implications of HIV/AIDS Infection" i.e. problems due to loss of financial security, and "The Socio-Cultural Implications of HIV/AIDS" i.e. problems related to role activities and status. Although these categories are distinct, they are highly interactive and causally related. For example, fatigue, weakness and skin sensitivity (physical implications of HIV/AIDS) affects the woman's ability to undertake the activities expected of a wife and/or mother; it also affects her ability to continue in paid employment. Loss of social role leads to feelings of anguish and hopelessness (psycho-emotional implications of HIV/AIDS) and loss of paid employment leads to loss of social role and economic hardship (economic implications of HIV/AIDS) both of which lead to anguish, etc. (psycho-emotional implications of HIV/AIDS). Economic hardship, in turn, prevents the purchase of
antiretroviral medication, which allows the clinical manifestations of the disease to persist or to worsen. In addition, the diagnosis of HIV/AIDS infection leads to social isolation (socio-cultural implications of HIV/AIDS) which, in turn, leads to loss of social role and paid employment which lead to hopelessness, anguish (psycho-emotional implications of HIV/AIDS) and the inability to purchase appropriate medication (economic implications of HIV/AIDS) etc.

The Physical Implications of HIV/AIDS

The clinical manifestations of HIV/AIDS can affect the lifestyle of infected people, both in the symptomatic and so-called asymptomatic stages (see above, Chapter 2). Participants in this study reported a range of seriously debilitating symptoms, which disrupted their normal activities. Here, again, although symptoms were experienced as distinct, they were clearly highly interactive and causally related:

_I tried to find a new job, such as physical work. But I could not stand the heat. I couldn’t stay under the sunlight...I’m a bit tired. I’m losing my appetite. I feel like exhausted, weak. It seems that I do not have enough energy to be able to do normal activities...I have sores in my mouth. It makes it difficult to eat much. My mouth is painful._ (P 1)

This participant recognizes that her loss of appetite is related to her fatigue; she also realizes that it is compounded by the sores in her mouth, which make eating painful. Even if her mouth was not sore, however, she might not have the energy to eat.

Some of participants had visible AIDS-related symptoms, for example, skin sensitivity, skin lesions and severe weight loss, and the latter two were strongly associated with the expected level of stigmatization in the villages:
I got nodules on my arms and legs. When mosquitoes bite me, it is very itchy. I don't want anyone to see my nodules on my arms and legs. (P 17)

I was very thin...I couldn't sleep. I kept losing weight. Everybody realized I was very thin. (P 19)

Nowadays, I am not healthy. I easily have an allergy to anything and break out in a rush. My parts body are sensitive and itch even when I touch water. I wish to become healthy again because when there are rashes on my skin, I get so irritated that I cannot do my job. (crying) (P 15)

My health is not good. I have gastric ulcers and suffer from stomachache and vomiting. A doctor tells me that I cannot eat spicy food or I will vomit. When I get headaches and feel sick, I take drugs from the hospital...I had to quit work at the orchard gardening because it is hard work where I am exposed to lot of insecticides. I could not do it. (P 12)

Some voluntarily gave up paid employment in the hope of avoiding or delaying the onset of clinical manifestations which they had witnessed in others:

I do not want to work as hard as before because I think my health would get worse. I also avoid sunlight because I am afraid that I may become ill. I tried to find indoor jobs like sewing to make money for my family's expenses. (P 7)

I used to do gardening and farming. But I quit when I learned that I am infected with HIV. I saw some PWAs work outdoors. They had an allergy to sunlight and some broke out in rashes. Some became ill. I am afraid of headaches. I am also afraid that I will be tired because the sunlight is very hot... I am afraid that my health will get worse or I will become ill. (P 8)
The Psycho-emotional Implications of HIV/AIDS Infection

Data analysis revealed that the psycho-emotional implications of HIV/AIDS infection included not only responses/reactions to a positive HIV/AIDS diagnosis (shock, denial, anger, fear, sadness) but also to lack of certainty about their husband’s and their own diagnosis until it had been confirmed.

Lack of Diagnostic Certainty

Twenty of the twenty-four participants suspected HIV/AIDS infection when their husbands developed AIDS related symptoms. Their suspicions were aroused because of their husbands’ use of CSWs and because they had learned about AIDS symptoms from AIDS-related education programs on radio and television.

These women were aware that their husbands used CSWs for extramarital sex but, because of the traditional status of women in rural Thailand, and the way male sexual appetite is designated (i.e. as sacrosanct), most felt unable to object. Those that do object, however, fail to change their husbands’ behaviour:

*I was aware of the high risk of him contracting HIV from CSWs. He told me it was none of my business. I don’t know how to control him. I have no choice. He always gives me money...he is the bread winner in our family...I used to ask him to wear a condom to have sex with me. But he never used one. He said he didn’t like them.* (P 24)

In addition, at least one participant actually encouraged her husband to use CSWs when she was pregnant:
I got married with my first husband when I was 18 years old. I didn't know him before marriage...um...my parents arranged it for me. He lived in another province. After my marriage, I moved to live with my husband's family. I did everything in that house. I thought if I stay with his family I have to accept everything in that place. I should obey his parents. Even when my husband always goes out at nighttime. I have no right to complain...

...besides, I was younger than him. I should respect him as well. I think that a man normally visits prostitutes...and...When I was pregnant, I told my husband to visit a prostitute. I feel it is better than he gets a second wife...um...I think my husband got HIV from the prostitute. (P 21)

The AIDS-related symptoms which initially raised the suspicions of participants were varied:

My husband had got diarrhea and I took him to the hospital. The doctor suspected that he was infected with HIV and ordered the test; the test was positive. (P 4)

My husband had a lung problem. After a long treatment his condition didn't improve. The doctor became suspicious and asked permission to do the HIV/AIDS blood test. It was positive. (P 5)

In May, my husband was taken ill. He had a seizure, he was confused and was barely able to move. So I took him to the hospital. He was treated at the government hospital for 2-3 months. The doctor couldn't diagnose his illness. However, the doctor suspected that my husband had developed AIDS and asked to perform a blood test. Three days later, the doctor told me that the test was positive and my husband had AIDS. (P 6)

Knowing that their husbands were infected with HIV/AIDS quite naturally led these women to wonder if their husbands had infected them. None of these women had
ever worked as commercial sex workers nor had sexual relations with anyone other than their husbands:

*I wanted to know whether or not he was infected. After I learned that my husband was infected, I wanted to know if he had infected me. I was scared and sure that I had been, but I wanted to know. I went to the hospital for a blood test so that I knew... I felt a little scared...uh...but I also wanted to know the truth.* (P 3)

One participant learned that she was infected by chance. Her husband was a regular blood donor and donor screening had identified his HIV infection. She wondered if her husband had passed the disease to her through their marital relationship:

*My husband normally donated his blood every three months. After the blood test before his last donation, he was informed that there was a problem with his blood. He went to see the doctor who informed him that the results showed that he couldn't donate his blood. The doctor told him that he had AIDS. After I found out that my husband was infected with HIV, I wanted to find out if I was infected. I took the blood test without advice from anyone else.* (P 18)

Another participant only discovered she was HIV positive following the diagnosis of her one-year old daughter:

*My daughter got sick with diarrhea when she was only one year old. I took her to the hospital... the doctor wonders about my daughter because she is very thin. He asks permission to test my daughter's blood... I want to know what her disease is... And then the doctor told me her blood test was positive.* (P 10)

(This woman had undergone a blood test during pregnancy, but this had not included screening for HIV.)
For other participants, those who were pregnant, their doctors suspected infection:

*When I was pregnant with my second child... the doctor advised me to have a blood test. At that time I thought I wasn't infected. The doctor gave me much advice so I decided to go through with the test. My test was positive and the doctor advised me to have the second test to confirm it. And the result of the second test was also positive.* (P 9)

**Reactions to a Positive HIV Diagnosis**

The initial reaction of most of these women to their HIV positive diagnosis was one of shock, followed by a number of other profoundly negative emotions associated with grief and loss. These included denial, anger, continuing anguish and hopelessness. In addition, they were beset by a range of fears some of which were causally related to their feelings of grief and loss.

**Shock**

Irrespective of their understandable desire to confirm or disconfirm their suspicions that they had been infected with HIV by their husbands, most confirming diagnoses were accompanied by profound shock. These women could not believe that they had contracted HIV/AIDS; they believed that they had done nothing to deserve it:

*Really shocked. It's really shocking. Why me? I haven't done anything wrong...It shouldn't happen...I told my husband. He didn't believe it.* (P 2)

*It's like a dream. It's not true. It's impossible. I can't believe it.* (P 6)
I was shocked because I never expected it could happen to me. (P 7)

Denial

For many of the participants, shock was followed by a period of denial. Some wanted their diagnosis reconfirmed by a second blood test:

I couldn’t accept the fact...so we got another blood test at another hospital, hoping that the first had been an error. (P 2)

I couldn’t accept it. I was confused and doing nothing but crying. (P 4)

I cried everyday. I couldn’t accept it... I never thought it would happen to me. (P 19)

Anger

Somewhat ironically, even though many of these women had colluded with their husbands' practice of visiting prostitutes, they were very angry with their husbands when their own infections were confirmed. Some severely reprimanded their husbands; others wanted to leave them, albeit temporarily:

I didn’t want to look at my husband’s face. Didn’t want to talk to him. I wanted to go out of his life, as far as I could. I didn’t know what to do...I cried everyday. (P6)

I was very angry with my husband. I scolded him and he accepted that it was his fault. (P 7)

I was very angry with my husband. I beat his face. Uh...I really felt angry with him. He passed on this disease to me. (P 21)
This initial anger, however, tended to be replaced by a concern for their husbands, especially when they began to show signs of serious illness. All of the participants willingly cared for the husbands who had given them and sometimes their children an incurable and severely stigmatizing disease. They did this out of love but also because of krenjai (i.e. a sense of obligation to protect the other from psychological discomfort, even at the expense of one’s own convenience or comfort):

I felt very angry with him. He passed on this disease to me. Then, within a couple of weeks, he was very sick. He felt exhausted and weak... um... he couldn’t look after himself we were really concerned about him. He blamed himself that he was infected and passed it on to me. He said he was very sorry... um... When he was very sick I felt sympathy for him. If I scold him, it is not useful; I try to think about his good things rather than his shortcoming... Um... he consoled me that in future there would be a cure for AIDS. I felt then that he was concerned about me. Um... so I felt I love him. I was not angry with him so I looked after him until he died... he was sick for about 3 months.

... I took care of everything for him. I bathed him. I also fed him and washed his clothes.

... I should do a wife’s duty. I also want to look after him. I love him. I’m willing to do it. (P 21)

I wanted to look after him and I should. I am willing to care for him. Because I am his wife, I feel it is a wife’s duty. I mean, a wife should look after a husband when he gets sick. I don’t want to leave him. If I don’t look after him, who will care for him?

... I felt krenjai for him. He is my husband. Normally he looks after me. He also gives me money. He works but I don’t work. I should look after him when he is sick. I do my best. (P 24)

I felt krenjai for him. He is my husband. I felt I should look after him and also wanted to care normally for him. I should give him emotional support. Besides, in northern culture, when our husbands are sick with any disease we will look after them even though we have to sell our things like gold necklaces for medication. I will do my best for him. I
saw that he was very ill and getting worse. I shouldn't leave him alone because he is my husband. (P 21)

Although participants were angry with their husbands, temporarily at least, they also targeted their anger at other people and organizations they considered implicated in their infection. One participant was angry with a doctor who had failed to screen her for HIV during her pregnancy:

I was so angry with the doctor. My kid was only one year old when I knew the result. Um...during pregnancy I had my blood tested...The doctor said he checked everything. The blood test showed everything was normal and I was relieved. Uh...then the doctor said he had not checked for AIDS. I was so angry with him...I think they failed me...Now the result of the blood test shows that my daughter and I have AIDS...I am very angry with the doctor, and even now I am still angry with the hospital. (P 10)

She responded by discharging herself and her daughter from hospital as soon as she found out:

I am really angry with the hospital. At that time, I took my baby away from the hospital immediately, although my daughter was being given intravenous fluid transfusion...In tears, I held my child in my arms and took her to a nearby community health service to take off the IV. (P 10)

**Continuing Anguish**

Some participants described experiencing a period of anguish, which appeared to be heightened by exposure to news, posters and television programs relating to HIV/AIDS:

I lost my morale especially when I saw an AIDS campaign on TV. They announced that there's no cure for an AIDS patient. I was so anguished when I heard that. I was certain I would die soon. I saw the
campaign so often. It made me feel that I was doomed and banished from society. It made me suffer. (P 4)

I felt heartache, sorrow, anguish, like something is squeezing my heart. When I saw a campaign poster at a hospital. It made me suffer. I was pregnant at the time. The picture on the poster described how AIDS is transferred from the mother to her baby. When I saw that poster I really felt heartache. (P 18)

Hopelessness

Some participants were clearly grieving for the loss of their future; the recognition of such a loss led to feelings of hopelessness:

I had never thought before that my future would end. It seemed like there was nothing at all. My life was hopeless. I wanted to die. I cried with my husband. I didn’t know what to do and felt very desperate. (P 10)

Suicidal Ideation

These feelings of hopelessness sometimes led to suicidal ideation and, occasionally, to actual suicide attempt:

There’s nothing left. What do I have to live for? I wanted to end my own life...I thought of nothing else but death. I didn’t want to live knowing that eventually I’d die soon. (P 8)

I fainted a couple of times. I cried a lot. I had no morale and didn’t want to do anything...I swallowed insecticide with my husband. But my mother found out and rescued us. She took us to the hospital. (P 16)

Fear

Once their seroconversion had been confirmed (and sometimes confirmed twice; see above), participants voiced a variety of fears; these included fear of the disease itself, fear for their children’s future and fear of discrimination.
Fear of HIV/AIDS

These women were very fearful of what HIV/AIDS would entail for them in the longer term. Their fears were fuelled by seeing other people with signs and symptoms of the disease, particularly their husbands (see above) and sometimes their children. Fears were also fuelled by what they heard of HIV/AIDS through the media:

I’m afraid of the illness. I saw others with AIDS. Some had very severe symptoms like many nodules. I am really scared about the illness in future...and...I saw my husband. He was very sick. He had nodules on his arms and legs. He was also diagnosed as having diabetes mellitus. (P 24)

He had lesions like herpes simplex and he looked skinny ... he felt exhausted and weak... he couldn’t look after himself. ... he wasn’t well and had a rash all over his body ... he got nodules all over his face and mouth...he got diarrhea...he lost his appetite...papules in his mouth. (P 3)

My daughter got sick with diarrhea when she was only 1 year old ... she was very thin. (P 10)

I learned about these symptoms from the media, for example, radio, TV...(P 24)

Fear that their children will contract the disease

Participants who were pregnant when they learned of their diagnosis were understandably fearful that the child they were carrying would contract the disease.

One participant went so far as to consider a termination of pregnancy:

I was afraid that my child would get the disease from me. If that’s the case, what shall I do? I’m very worried who’s going to look after him? I wanted an abortion because I wasn’t sure if my child would get
the disease from me. I pondered it again and again. I talked with my husband. Then we consulted with the doctor at the hospital. They suggested I not have an abortion. I came back home and talked with my husband again. We took a lot of time to think about this. Finally, we decided not to have an abortion. So now we have this son. (P 13)

For others whose diagnosis followed childbirth, they feared that the child had been infected:

I was worried about my daughter I was really concerned about her. I checked her blood. She's got HIV as well. I cried for about a week. (P 21)

Fear for children's future

These women knew that they had an incurable disease from which, sooner or later, they would die. The welfare of their children when they became incapacitated or died was a constant worry. Thus, although they were afraid of becoming sick and dying, they were even more afraid of the implications of their debilitation and death for the wellbeing of their children:

The most fearful thing is being afraid of death. I am afraid that if I die, who's going to raise my daughter... I live in my house with only my daughter. (P 10)

I don't want to die. I want to live longer with my son. I don't want to get sick. I am very concerned about my son. I want to see his graduation and see him get a job. (P 12)

Fear of discrimination

HIV/AIDS is known to be an incurable and infectious disease. In addition, because of its routes of transmissibility, it is seen as a "dirty", i.e. it is a seriously stigmatizing
disease. Participants were aware of this and feared social rejection from their families and friends:

*I'm very afraid of being rejected by my neighbour. I dare not go anywhere or do any thing.* (P 15)

*I am afraid of being rejected because I am not an ordinary person. I'm infected with HIV.* (P 20)

Degrees of discrimination appeared to be associated with the visibility of known AIDS-related symptoms:

*My neighbours didn't believe that I had AIDS. They said I looked healthy, not like sick.* (P 2)

*I try to take care of myself. When I go anywhere, I will take a bath and wear clean clothes so that others will not think I am dirty.* (P 10)

*I don't want anyone to see my nodules on my arms and legs. I'm afraid of discrimination.* (P 17)

The Economic Implications of HIV/AIDS

The HIV/AIDS epidemic in Thailand has led to regular screening programs in some industries (Ritchie, 1998) and this, together with fear of discrimination and the physical limitations imposed by their HIV/AIDS, leads many to leave their normal employment and seek alternative employment elsewhere. This is true for both women and men. In addition, however, because the male is the traditional primary breadwinner in Thai families, the loss of a husband’s well-remunerated employment affects the whole family. In the absence of government provided welfare services (the
Thai government withdrew one third of its assistance to HIV infected people in 1997) and in the face of escalating medication costs, such families face economic crisis.

**Forced Resignation from Employment**

Many companies require their employees to be screened for HIV/AIDS every 6 months. However, because they cannot afford the medication required to treat those who are seropositive, or because employers fear loss of business resulting from employing PWAs, many are asked to resign. In addition, many are compelled to resign by the discriminatory behaviour of their work-mates:

*I had worked in the sewing factory for a few years...When the factory manager found out, he didn’t want me to work there anymore... I used to earn 2,000 baht/month.* (P 17)

*My colleagues learned that I had AIDS. They didn’t come close to me. I couldn’t work at that factory. I had to quit the job. No money.* (P 20)

*When I worked in a restaurant, the owner told me that if customers knew I had AIDS, they would not patronize his restaurant anymore. So, he asked me to quit. Since I quit I earn no money.* (P 16)

**Voluntarily Resignation from Employment**

To avoid this embarrassment, some people who are aware of their HIV positive status resign voluntarily and try to find suitable work elsewhere:

*I had to resign from my job, although I didn’t have any problems...When I got the result, I decided to quit my job because my factory wanted to blood-test every 6 months.* (P 4)

*I had to quit my job. Previously, I worked in a factory and they wanted my certificate every 6
months. They wanted to know my health status, but if anyone had a positive result it meant that they showed up as positive. He or she would decide to voluntarily resign. (When I resigned, naturally, my income decreased.). (P 8)

People resign their positions either prior to their blood test results becoming known or to prevent them becoming known, because of the stigmatizing nature of their disease. They fear discrimination from work colleagues:

I was afraid of being ostracized; I took cloth fabrics and sewed them at my house. I used to work in a cloth factory...I felt uncomfortable...I knew what I should do. I requested my boss to bring me cloth fabrics to sew at home. I felt better than if I worked at the factory. My income has decreased. (P 11)

I had to quit. Previously, I sold fresh food such as chicken meat. I was afraid that people might be disgusted and dare not buy things from me. I therefore decided to stop selling meat, and my income has decreased. It serves me right, because formerly when I knew an AIDS person was selling food, I wouldn't buy anything from him or her. (P 14)

Loss of Own Business

One participant was a dressmaker who had her shop at home. Customers ceased to come to her for dressmaking as before:

My income has decreased. The customers disappeared when they knew I had got AIDS. They are afraid of catching the disease from me, I thought. (P 6)
Loss of Primary Bread-Winner

As indicated above, in traditional Thai families the husband is primary bread-winner.

This means that should be become incapacitated or die, the whole family will suffer economically:

My husband died. After he died I had no security. In the past I was employed in a temporary job with the government. My husband told me to quit that job after I had our daughter because he wanted me to look after our daughter at home. When my husband died, I had no income... (P 24)

Appropriation of Property by In-laws

In some cases, the loss of a husband to HIV/AIDS and his primary bread winning capacity is exacerbated by the appropriation of the couple’s property by the deceased husbands’ parents. One participant found herself bereft of the business she and her husband had established and had to resort, finally, to leaving with only a television and refrigerator:

When I stayed with her (mother-in-law) my husband and I had a chicken farm. She managed our income from the farm. I only got money from selling eggs...um...she said she would use the money to build us a house. She spent around 200,000 Baht to build the house. After my husband died, she sold the house. She didn’t give me the money. Um...my husband and I bought a truck. She sold that truck and didn’t give me the money either. I didn’t know what to do. I didn’t complain...finally I got the TV and refrigerator and took them back to my hometown. (P 21)

Costs of Medication

All of these women were infected by their husbands and some, in turn, infected their children. This could imply that two or three (perhaps more) people in each
HIV/AIDS affected family required anti-HIV medication. It is expensive and acquiring the funds to purchase medication is problematic and can entail considerable sacrifice elsewhere:

*I sold everything. I sold my gold necklace, video...tape-recorder...* (P 10)

Another participant was already thinking about what she would do when she became ill:

*When I become ill I will have to pay for it. It is a big problem.* (P 24)

Yet another had taken on the funding of her own medications when the government withdrew its subsidy:

*I pay 500 Baht for a health card which I can use in only 2 hospitals, Sankumpang and Nakornping. I can have treatment for free. Previously I had a subsidy from SONB (government) around 500 Baht. Now the government has cut all subsidies because of the economy.* (P 2)

The Socio-Cultural Implications of HIV/AIDS

As indicated previously, HIV/AIDS is perceived by northern Thais not only as an incurable infectious disease, but because it is seen as being transmitted through dubious, or “bad”, behaviours, it is seen as unclean or stigmatizing.
Northern rural Thais live in tightly knit communities, where the closeness of their dwellings reflects the closeness of their social relationships. This closeness, however, impacts negatively on people with HIV/AIDS infection; they have an infectious disease which relatives and friends do not want to catch. Through a range of strategies, therefore, neighbours and friends seek to remove themselves from the risk of infection. Such strategies are perceived by people with HIV/AIDS as social discrimination (Danziger, 1994; Gilmore & Somerville, 1994; Songwathana, 1998). It has already been noted that people with the visible signs of HIV infection are subjected to the worst discriminatory practices (Weitz, 1990).

Northern Thai women with HIV/AIDS infection expect to experience at least some discrimination. They understand how others construe HIV/AIDS through their shared culture by imaginatively taking the role of the generalized Thai village ‘other’. Indeed, at least one participant (P 21) admitted to ostracizing PWAs before she became infected. They not only understood the behaviours and perceptions of the ‘other’, but also how to fit their actions (Blumer, 1969) to the actions of the ‘other’. They knew, therefore, how HIV/AIDS is designated in northern Thai villages and acted appropriately according to this designation. These appropriate reactions are addressed fully in Chapter 6, under ‘Hiding Out’.

Discrimination, in this study, took many forms and led to participants feeling different and unworthy. Firstly, they were “looked at” very pointedly by village neighbours and, secondly, they were “kept at a distance” by neighbours, friends and even some family members. In addition, PWAs were “looked at” and “kept at a distance” both
on an everyday basis and episodically, at culturally significant events. The family members of PWAs, particularly their children, were also targets of discrimination.

Being Looked At

When participants described themselves as being “looked at” they were referring to very pointed ‘looks’, the sort of ‘look’ they did not elicit before they became known as PWAs. “Being looked at” in this particularly pointed way was to ensure that PWAs recognized that they had been designated as undesirable in villagers’ object worlds and, because of their shared enculturation, PWAs did recognize that they had been designated in this way:

They looked at me as unusual... the villagers looked at me. I felt uncomfortable. (P 21)

...and when I attended cremations, people looked at me. I think they reject me. Sometimes no-one talks to me. I have no friends...I sit down by myself. (P 24)

Being Kept at A Distance

Having “looked at” PWAs to designate them as abnormal and, particularly, infectious human “objects” and ensure that they appreciated their new designation as ostracized people, villagers implemented a variety of strategies to avoid the risk of infection from such ‘objects’. These strategies are related to both “everyday” and episodic activities and are all aimed at keeping their distance from possible infection.

Family and friends of PWAs, on an everyday basis, kept their distance from possible infection by remaining physically distant from the PWA and any food, water or utensils which she might (have) touch(ed) (and contaminated):
When I mixed with people, they would try to keep their distance from me by not sitting close to me. Normally they were not like this. (P 20)

My friends kept away. Before, we could talk together. But at this moment, we can't. They don't come to talk as before. For example, some families who I visited and drank water in their house, threw away the glass I used. I saw. (P 10)

My neighbour and my sister are afraid of me. Even when I went to eat at her house, she immediately cleaned up and disinfected my glass and plates. I saw her do that. Prior to having the disease I used to have food with her and my neighbour very often. They never did this to me. (P 15)

Some families who I visited and drank water in their houses, threw away the glass that I used. I saw they did...I feel that they were so disgusted with me. (P 3)

Some villagers made absolutely sure the PWA became aware of her new designation by saying hurtful things within earshot and ensuring that she was kept at a distance:

*There are so many people that don't want to get close to me. They don't want to talk to me. They told their children not to come close to my child. They intentionally let me hear all of that. They don't care how I feel.* (P 19)

Being kept at a distance leads to the denial of even mundane, everyday courtesies to PWAs; even water is withheld. (In rural Thai villages, houses normally have a jar of water and dipper outside which visitors use to refresh themselves.)

*Some villagers reject me very much. They don't give me any water. They tell me that the dipper doesn't work. I know myself they don't want me to use their dipper. They hide their dipper.* (P 16)
Also on an everyday basis, shopkeepers, particularly those who sell food, keep PWAs at a distance. They do this because they, too, are afraid of becoming infected and/or because they are afraid other customers will cease to frequent their shops:

*When I went shopping, the storekeepers said that if someone saw me, people would not patronize their shops again. So they refuse to sell things to me.* (P 3)

*They reject me. Shopkeepers in some shops tell me to pick the goods by myself and put money on the table. They don’t receive money from my hand.* (P 16)

*I wanted to buy some pork at the market but the seller wouldn’t allow me to touch it. She said if I want some pork just point to it but don’t touch it. She also told me not to come close to her shop.* (P 21)

Participants were also kept at a distance at food stalls and in restaurants; this could take the form of being asked to take home their meal or of other customers electing to take their meals home:

*When I want to eat at a noodle stall, all the customers move away from me or turn away from me while they are eating. Some are more tactful and take the food back home to eat.* (P 1)

*Last month I went to eat at a noodle stall and the vendor said to me that I should take the noodles back home to eat. It seemed like she didn’t allow me to eat in her place. I know she rejected me even though she didn’t tell me directly. So I have to take away the noodles and eat at home.* (P 10)

People also appeared fearful of eating food prepared by PWAs because, again, they were afraid of becoming infected through it:

*Previously, I used to sell papaya salad. My business went well. My customers said it was delicious and many people came to buy it. When they learned that*
my husband had become sick from AIDS and I had AIDS as well, they stopped coming to buy papaya salad from my place. I couldn’t sell any more. (I had to close my shop.) (P 12)

‘Keeping their distance’ from PWAs and/or food prepared or handled by PWAs also extends into culturally significant events such as marriages and funerals:

At his funeral (husband’s), many neighbours came. But no one ate the food. They also stayed away from his coffin...uh...some covered their mouths and noses with a handkerchief. Someone said she was scared the disease was spread by air. (P 21)

At events such as marriages and funerals it is the traditional role of women to prepare, cook and serve food. Women who are HIV positive, however, are denied their normal role participation and this appears to be experienced as particularly painful:

When my friend’s daughter got married, I went to help in the kitchen. I really wanted to help my friend. I started to cut vegetables, thinking that would help them finish sooner. But when other people saw me cut pumpkin, they said I shouldn’t do it. I knew immediately. I said ‘how could I cut myself’. They feared my blood would mix in the food and they may become infected with HIV. I cried and went back home immediately. (P 15)

In northern Thailand, at events such as funerals, the village women gather to cook in the home of the deceased. The traditional dish at such events is ‘Larb Dip, which is made from uncooked beef or pork with fresh animal blood, and herbs. Women who are HIV positive are not allowed to cook ‘Larb Dip’: “Who will dare to eat it?” (P 8)
Families of PWAs Being Kept at a Distance

The socio-cultural implications of HIV/AIDS also affect the families of PWAs; people attempt to keep their distance from the children of PWAs and (incredibly) even their dogs. The most common means of keeping the children of PWAs at a distance is to require their withdrawal from school:

Some children came to play with our children. The villagers said 'don't play with my son, his father died of AIDS'...I took my son and put him in a foster house. They didn't accept him when they found out my husband had died of AIDS. They asked me to take my son back. They said it wasn't because they felt disgusted, but that other people would take their children away if my son was there. So I took my son back home, I cried with my parents. (P 9)

My son was not allowed to go to school. A teacher said that my son might catch the disease from his father. She said that my son might bite other students and cause them to catch the disease. If the school took my son, all other parents would take their children out of the school. My son, therefore, had to withdraw from that school. (P 17)

I couldn't put my son in school. The teachers immediately turned to me and said they couldn't take my son because other villagers were not happy. They didn't want my kid to mix with their kids because they were afraid they would catch AIDS. The teacher said he understood me. But he only understood superficially. He said infected people are part of our society. However, deep in his heart, he does not accept this. (P 18)

When my daughter was two and a half years old, I took her to school near my place. She went to school for around three months. The principle of the school told me that I have to withdraw my child. There were 4 or 5 children withdrawn from the school because of my daughter...um...my daughter likes to go to school so much. She always cries and asks me to take her to school. (P 21)
And even when children are allowed in school, subtle stigmatization persists; the personal utensils and equipment of the children of PWAs are kept at a distance:

*My child can come back to school again. But she has to separate her stuff, for example, her glass, her spoon.* (P 21)

Villagers even ensure that family pets are kept at a distance from PWAs:

*My sister in law lives very close to my place. I gave my food, which I hadn't eaten to her dog. She said don't feed her dog. Why does she really reject me so much? Why? I think my disease will not jump up to her.* (P 10)

These continuously discriminating activities serve to re-emphasize for the woman with HIV/AIDS that she is designated as abnormal, as undesirable. She is stripped of her traditional roles and as a result, she feels both isolated and worthless. She yearns for her life to be like it was before she became infected:

*I need nice neighbours who do not reject me because I am infected with HIV. I want friends who understand me. I need my neighbours to love me. I want them to be like before, when we could talk together. They said I was very good at cooking. But now they don't come to talk and eat as before. They keep away from me. I feel they really reject me.* (P 10)
Summary

The dominant or basic social problem faced by the participants in this study was “Surviving With HIV/AIDS”; they had to survive with HIV/AIDS because, up to the present time, they cannot survive HIV/AIDS. Surviving With HIV/AIDS is problematic in rural, northern Thailand not only as a result of the clinical manifestations of the disease, but also because of the way HIV/AIDS is socially constructed. Both of these impeded the participants’ ability to undertake the normal activities of a kulasatrii and mae.

“Surviving With HIV/AIDS” was a psycho-motivational orientation to their disease, which developed in response to the issues and problems which prevented them from carrying out their normal social role activities. Data analysis revealed that participants confronted four distinct but highly interactive and causally related groups of problems. These were “The Physical Implications of HIV/AIDS”, “The Psycho-Emotional Implications of HIV/AIDS”, “The Economic Implications of HIV/AIDS”, and “The Socio-Cultural Implications of HIV/AIDS”.

“The Physical Implications of HIV/AIDS” included a range of debilitating symptoms which disrupted their normal activities and which interacted causally with the expected and actual degree of discriminatory behaviour participants experienced.

“The Psycho-Emotional Implications of HIV/AIDS” included a range of profoundly negative emotions related to grief and loss (shock, denial, anger, continued anguish, hopelessness and suicidal ideation) and a range of fears, including fear of the disease,
fear that their children will contract the disease, fear for their children's future and fear of discrimination.

"The Economic Implications of HIV/AIDS" result from a range of interacting factors. Firstly, the epidemic in Thailand has led to regular screening programs in some industries; a positive diagnosis has serious cost implications for employers (for treatment) who avoid these by requiring infected employees to resign. Secondly, some employees voluntarily resign to avoid such 'public' embarrassment. Thirdly, the businesses owned by PWAs suffer when diagnoses become public. Fourthly, loss of the primary bread-winner, that is, the husband and, fifthly, the risk of appropriation of property. All of these drastically reduced the earnings and/or financial security of participants. In addition, their economic status was further jeopardized by the costs of medication and the Thai Government's (1997) reduced financial aid to PWAs.

"The Socio-Cultural Implications of HIV/AIDS" are a result of rural, northern Thais' construction of HIV/AIDS as highly infections and "unclean"; PWAs in this study, therefore, experienced severe stigmatization. This stigmatization took three distinct forms both on an everyday basis and episodically, at culturally significant events. Participants were "looked at" in especially pointed ways by fellow villagers, they were also "kept at a distance" and their families were also 'kept at a distance'. In symbolic interactionist terms, all of these behaviours were used to inform participants that they had been designated as unworthy, undesirable individuals. That participants correctly interpreted such behaviours (from the perspective of the generalised other) and responded appropriately will become obvious during the discussion of 'Hiding Out With HIV/AIDS' in Chapter 6.
Chapter Six

Hiding Out and Hanging In: Surviving With HIV/AIDS

Introduction

The aim of this study was to explore and theorize how married or widowed Thai women in the rural north manage and cope with HIV/AIDS. Data analysis revealed that they were dealing with the basic social problem of surviving with HIV/AIDS. The participants in this study used two complementary social processes to achieve this. These were “Hanging In with HIV/AIDS” and “Hiding Out with HIV/AIDS”. This chapter will provide a detailed description of these social processes and provide excerpts from the data to support the analysis.

These two processes enabled participants to come to terms with the fact that they had an incurable disease and, indeed, make the best of their predicament. They also enabled the women to shield themselves and those close to them from the social discrimination which typically accompanies the disease. Whether they decided to ‘hang in’ or ‘hide out’ was a function of the context within which they found themselves. For example, participants with visible lesions would focus on hiding such lesions from friends and neighbours, that is, “hiding out” whereas those without visible signs of the disease would focus on acting or behaving ‘normally’, that is, ‘hanging in’.

In addition, these processes were mutually exclusive; participants could never both ‘hang in’ and ‘hide out’ simultaneously. The more participants focused on hiding out,
the less time (and energy) they had to ‘hang in’. Of course, as their disease progressed, the participants were less able to ‘hang in’ and ‘hide out’; the ravages of advanced disease robbed them of the energy and will to do this. Quite literally, therefore, participants died when they were unable to ‘hang in’, in particular.

As with “Surviving With HIV/AIDS”, both “Hanging In” and “Hiding Out” were complex, fluctuating phenomena, which varied in dimensions. Again, they were expressive of psychologico-motivational orientations, which enabled participants to cope with and manage their disease. Similarly again, these orientations were rooted in the women’s interpretation of familiar symbols (gestures, words, behaviours) and their understanding of these through the perspective of the generalized other.

**Hiding Out and Hanging In**

‘Hiding Out With HIV/AIDS’ was the process through which participants tried to conceal their disease (and that of other family members) from neighbours, workplace colleagues, etc. It involved a number of subprocesses; these included protecting their husbands, their children and themselves.

‘Hanging In With HIV/AIDS’ was the process through which participants made the best of their predicament. It involved a number of subprocesses; these included resolving to fight for life, being accepted by others, acting normally, accepting support, actively seeking support, seeking financial assistance, following a healthy lifestyle and making merit.
Hiding Out With HIV/AIDS

HIV/AIDS is still designated as a seriously stigmatizing disease in northern Thailand; when people become infected, therefore, they know that they should expect to experience social discrimination and ostracism. They also know that they can expect those others in their families who are also infected to experience discrimination. In order to avoid such expected discrimination, they ‘hide out with HIV/AIDS’. "Hiding Out" in Thai villages can, however, be difficult; villagers live very closely one to another and know most things about each other.

Hiding out with HIV/AIDS refers to any active strategies implemented by participants to protect themselves, their children and their husbands from the discrimination associated with HIV, and in this sense can be construed as ‘extraordinary’ activities. Clearly, however, the more obvious the manifestations (e.g. lesions) or results (e.g. death) of the disease and the degree of discrimination/ostracism expected, the more participants concentrated on concealing their disease (and that of other family members).

What this implies, in social interactionist terms, is that the presence of visible and readily recognizable HIV/AIDS-related lesions and symptoms facilitates and/or expedites the designation of their bearers as Persons With AIDS. Participants knew this and, accordingly, attempted to conceal their lesions. As one participant stated:

I feel that I’m healthy, I have no symptoms and no sickness but I’m rather fat. (laughs) My neighbour said to me that I may not have AIDS. I look too healthy. (P 18)
Participants found it prudent, in light of the expected distress and/or discrimination the revelation of the diagnosis would entail, to protect themselves, their children and their husbands. They told lies and they altered their activities to conceal their own diagnosis, or those of close family members, from people who they expected would react negatively to it from the moment their or their family member’s diagnosis were confirmed. “Hiding Out”, therefore, is a mirror-image of “Being Kept at a Distance” (see above, Chapter 5). “Hiding Out” refers to the strategies which participants chose to implement in order to “distance” themselves from the hurtful discrimination they anticipated would result from public knowledge of their diagnosis. “Hiding Out” is a pointed illustration of these women’s ability to take the role of the other and adjust their behaviour accordingly.

Protecting Husband

As befits the nurturant-mother role of the kulasatrii and mae participants’ first thought, upon learning their husbands’ diagnoses, was to protect their husbands’ from the distress of the truth. They did not immediately consider the probability that their husbands had infected them:

I just cried. I tried to hide in the bathroom at the hospital to cry. I cried so much. I was afraid my husband knew that he was infected. I didn’t want to hurt his feelings. I told the doctor not to tell him that he had AIDS. He was very sick. (P 15)

Interestingly, these kulasatrii also attempted to protect their husbands from the ravages of the disease by encouraging a healthy lifestyle and providing emotional support. Clearly, therefore, they were attempting to assist their husbands to ‘hang in’ with HIV/AIDS (see below).
At the time I dared not tell my husband. I didn’t want to shock him. He might have wanted to commit suicide. I know his personality. He’s sensitive. I hide all my feelings. When he got sick he asked if he was HIV positive. I lied that he only had pneumonia. He asked if I had lied to him. I said that he really only had pneumonia. I tried to distract him by asking him out, trying to console him. I tried to tell him to look after his health. I gave him more emotional support. He is a heavy smoker and never listens to my warning to stop. (P 9)

I didn’t tell my husband. I told a lie to him that he just had pneumonia. However he knew himself that he had AIDS. I just tried to give him support. I think men are always like this. He then became very desperate when he knew that he was infected. His health deteriorated quickly and he died within one month. (P 12)

The kulasatrii continues to protect her husband, even after he dies:

The owners were very kind when my husband died...they gave me money to arrange his funeral. I told them that my husband died of another disease. (P 10)

Protecting Herself and Her Husband

Participants also told lies and altered their activities to protect the ‘family unit’ from probable discrimination. They knew that their husbands’ positive diagnosis would entail ostracism for themselves, too:

When my husband got sick I took him to my home town. Because I was afraid that if the neighbours knew he had HIV they would reject us. (P 21; my emphasis)
They behaved similarly when both partners were infected:

I talked with my husband and we decided to quit our jobs. We worked at the same shop in the city. He was a salesman and I was the housekeeper. We could earn around 5,000 baht a month. We decided to quit our jobs at the shop because we were afraid people would reject us if they knew we had AIDS. So we didn’t tell the owners of the shop that we got AIDS. They asked us why we were leaving. I told them a lie. I said I wanted to go home. (P 10)

Protecting Her Children

Many parents and some school teachers are afraid that their own and/or other children will become infected through contact with the children of HIV positive parents. In order to avoid possible infection, therefore, parents withdraw their own children from school. In addition, teachers who fear possible infection and/or who fear multiple withdrawals from their schools will refuse to admit the children of HIV positive people or, if already admitted, to require their withdrawal. Thus, the children of HIV positive people experience discrimination; if mothers are unable to shield their children from such discrimination, they feel guilty for failing their children (Brown, 1996). Again, therefore, in order to protect their children, HIV positive mothers lie about their disease:

When my daughter was two and a half years old I took her to school near our house. She went to school for around 3 months. The principal of the school told me to withdraw my daughter because 4 to 5 students had withdrawn from the school because of her. Two to three months later, the Head asked me to tell my story to other students' parents at one of their meetings. I went there and told them that I had AIDS but I lied about my daughter. I told them I had never tested her blood because I really wanted her to go to school that's why I told a lie because I knew my daughter had AIDS. (P 21)
They also find schools, which will enroll their children, even if it means travelling long distances in searing heat:

_I send my daughter to nursery (foster care) in another village that accepts her. That nursery helps parents who are infected with HIV/AIDS, but it is far from my place. I have to ride a motorcycle to bring her back home at 4 p.m. It is very hot but I have to endure this. I put a hat and a shirt on my daughter. I have no other choice. I have to do it. (P 10)_

_I send my child to school at...(another village). That school accepted my son, though it is far from home, it is good for my son to study. (P 18)_

**Protecting Herself**

Participants protected themselves from hurtful discrimination, by “Avoiding Social Contact” with people who reacted negatively to them and “Being Clean and Covered”. “Avoiding Social Contact” had three dimensions. The first was engaging in almost reclusive behaviour; the second, limiting their activities in the village; and, the third, resigning from paid employment. “Being Clean and Covered” had two dimensions; these were covering skin lesions, dark skin and weight loss (the common and easily recognised manifestations of advanced disease) and of always presenting themselves in public as clean (objects). Both of these strategies are appropriate responses in a culture that still designates HIV/AIDS as a ‘dirty’ disease.

**Avoiding Social Contact**

Avoiding social contact includes almost reclusive behaviour; some participants chose to withdraw almost entirely from village life to protect themselves from hurtful discrimination. In addition, at least one participant recognized that such hurtful
behaviour was designed precisely to ensure that she did withdraw ("I know what I should do"): 

*I live alone. I didn’t mix with them. I joined some parties sometimes...I know what I should do. (P 3)...and...Although other villages treat me badly. I don’t care. I live with my son and don’t mix with other people. (P 4)...and...I live only in my house with my daughter. I do not care about anyone. I do not go to join any activities in the village. (P 10)*

*Things aren’t the same as before. They aren’t normal. I have to be careful about what I do. (P 21)*

*I’m very afraid of being rejected by my neighbour. I dare not go anywhere or do any thing. (P 15)*

In addition, participants protected themselves from hurtful rejection by limiting their activities in their villages. Knowing that friends and neighbours still believe that HIV/AIDS can be transmitted in food and food utensils, they selectively avoided engaging in the preparation and cooking of food, both on an everyday basis and at special ceremonial functions. Participants contributed to such events (as all women are traditionally expected to do) by washing and cleaning up. Some participants were so sensitive to the attitudes of others, they refused to eat out at all, always preferring to eat at home:

*When I go to a funeral I do not share a meal with other people. I feel that other people reject me, so I come back to eat at home...because I am afraid that others will reject me. I always realize that if I go to a funeral or activity in the village, I will not have a meal with others who I am not close to...I will help others to clean up but I will not cook. (P 14)*

*When I go to a funeral or other activities in my village, I have to be more careful. I don’t help to cook, I am afraid that others will reject me. I prefer*
to help washing dishes, I feel better. (P 15)...and...I like to wash dishes more than cook. I am afraid that others would not eat the food if I helped to cook. (P 16)

I join some parties sometimes but I don’t help in the kitchen because they watch me and know I have AIDS. They are afraid and don’t like me helping out in the kitchen. I know myself. So I didn’t want to help them like I did before. (P 3)

Participants also chose to hide from possible hurtful discrimination by not going to the temple and by shopping in distant villages where their diagnoses were not known. In addition, participants also made important employment choices to avoid discrimination. They chose to leave factory work to work at home:

I used to work in a cloth factory. Even though the factory’s owner didn’t say a word about it, I was still afraid. I felt uncomfortable. She tried to convince me to come back to work in the factory like in the past. Nobody would mind. I knew what should I do. I requested her to bring cloth fabrics to sew at home. I felt better than if I worked at the factory. (P 11)

They also chose not to avail themselves of gainful employment outside their homes:

They invited me to work with them at the same shop but I thought, if they knew I had AIDS they may not ask me to work with them. I thought like that. So I prefer to work from my place. (P 24)

Being Clean and Covered

As already indicated, participants tried to conceal the obvious and commonly recognized manifestations of their disease because the degree of discrimination they experienced was associated with visible HIV/AIDS-related symptoms:
I always wear a long sleeved shirt and pants to cover the nodules on my arms and legs (she shows her skin lesion on both arms and legs). (P 17)

They also try to conceal the ‘dirtiness’ of their disease:

When I go anywhere, I will take a bath and put on clean clothes so that others will not think that I am dirty. (P 20)

I always clean my clothes myself because I am afraid that other people will be disgusted with me (she shows her clothes which look clean). I have a few nodules on my arms and I wear a long sleeved shirt to cover them. I don’t want anyone to see them. I always clean myself, especially when I go out. I will be careful. I don’t want anyone who looks at me to think I am dirty. (P 10)

Interestingly, although not strictly relevant to this analysis, children learn quickly how HIV/AIDS is designated in rural, northern Thai culture by observing the symbolic actions (gestures, words, behaviour) of others; they also learn to adapt their reactions appropriately to such designations. At least one child of one of the participants chose ‘Hiding Out’, too:

When my son knew that his father had got AIDS, he ran away from home. He was afraid of being teased by his friends. He studied in year nine at that time. He was absent from school and went to stay with his friend in the city. I tried to find him for many months. After five to six months he finally came back home. (P 6)
Hanging In With HIV/AIDS

Hanging In With HIV/AIDS is the second social process through which participants survived with their disease and, as mentioned previously, it is complementary to but mutually exclusive from Hiding Out. The more time and energy are focused on Hiding Out, the less there is available for Hanging In. Conversely, the less time and energy is spent on Hiding Out, the more there is available for Hanging In.

Hanging In, just like Hiding Out With HIV/AIDS, is a psychologico-motivational orientation which assists HIV positive northern Thai women to survive with HIV/AIDS. It is, as noted earlier the process through which these women make the best of their predicament. Hanging In is not the same as passive acceptance; the analysis will show that these women actively pursue the best life possible, given their disease. It is as if these women had read Florence Nightingale; they clearly wish to put themselves in the best possible condition for nature to work upon them. The best life possible is the life as near 'normal' (that is, pre infection) as possible.

_ I feel good because I feel like a normal person. I am able to work...I am asymptomatic. I live a normal life with my family._ (P 3)

Hanging In, as a process, did not begin until infected women had recovered from their initial shock of learning of their seropositivity and, possibly, resultant suicidal ideation. Hanging In commenced when these women resolved to fight for their lives. They resolved to do this for a number of reasons (to be discussed below); however, for those who have children, the desire to care for their children and to watch them grow and flourish is the overriding motivation. Fighting for their lives is easier when they see themselves as accepted, mainly by close family, and gradually come to be accepted,
mainly by neighbours who initially ostracized them. It is also easier the more ‘normal’ and ‘healthy’ the women themselves feel. Normality and health are expressed in the ability to carry out all the traditional roles of a kulasatrii and mae, including the ability to continue to contribute to the household’s finances.

Once participants had resolved to fight for their lives, they actively sought support, both socio-emotional and financial, from a range of sources to enable them to do this. Such support, once accessed, served to reinforce their determination to fight for their lives. The most important sources of support were participants’ mothers; upon the death of their husbands, all but one participant (and she desired to) returned to their original villages to live with or very close to their mothers. Mothers willingly provided both emotional and financial support, often at considerable personal cost. In addition, participants employed a range of other strategies to improve their economic status; they sought appropriate employment; they asked other family members for assistance; and, they applied to government and non-government sources.

A number of participants chose to re-marry, even when they did not love their new husbands. They remarried to ensure that either the participants themselves and/or their children would be cared for when they became ill, or died, or became orphans. They also remarried to appear ‘normal’.

A further, critical source of support for all participants was the Persons With AIDS (PWAs) Group. Many stated that these groups provided the sort of support they could acquire nowhere else. Indeed, for many of the participants, participation in the PWA
Group had been hugely influential in sustaining (and sometimes even increasing) their resolve to fight for their lives.

As well as actively seeking socio-emotional and financial support, participants chose to follow a ‘healthy’ lifestyle, sometimes incorporating activities they had previously avoided or failed to undertake. They selected their diets very carefully and avoided ‘taboo’ foods. In both cases, this was to maintain themselves in the best state of health. They also exercised regularly, and for the same reason. In addition, they both sought medical advice and took traditional herbal medicines to control (and even cure) their disease.

Finally, and as befits a Buddhist kulasatrii and mae, all participants undertook merit-making activities. They did this to improve their karma, that is, to live longer and more pleasant lives. Meditation, prayer, worshipping at the temple and feeding monks became regular activities; in addition, participants deliberately sought to be kind and generous to others.

**Resolving to Fight For Their Lives**

As discussed above, once participants had recovered from the shock of learning of their diagnoses, all of them resolved to fight for their lives. For many, the urge to live was a function of their love of their children:

> I tried to commit suicide, but when I thought of my son I could not do it (crying) I thought that if I died, there would be no one to take care of him. Therefore, I resolved to fight for my life and my son’s future. He is the hope in my life. (P 7)
I'm still alive because I have my child. I want to live with him as long as I can. I will take care of him well. He is strong. He is everything in my life. He is my morale that makes me fight. I am so worried about him. (P 18)

Others compared their own situation with that of others, and felt heartened by their relative advantage:

I compared my situation with them and I felt I am better off than them. Someone has three kids. After I saw and talked with them, it made me feel so strong and I cheered up. I thought that compared with many people, they were worse off than me. Why shouldn't I fight for my life? (P 21)

It took me approximately two months to accept that I had AIDS. Then I realized that I am not the only one in the world. When I went to Bangkok for a visit, I realized that the people with AIDS who lived in the slums of Bangkok were worse off than me. They didn't have someone to care for them, and they had more serious symptoms. I felt that I was better off than them; it boosted my morale very much. But when I saw them, I couldn't stop crying because I felt sympathy. (P 4)

It took a long time for me to accept the fact that I had AIDS. I thought that there are many people who have AIDS and many of them are still alive, so I shouldn't be scared and accept it. I also thought that all people would eventually die, not only people with AIDS. That helped me. (P 19)

For yet others "fighting for their lives" was a strategy to keep them alive until curative drugs become available:

But I need a new medicine that can cure me. I'll wait for new drugs. I will buy them no matter how expensive they will be. Just like buying back my life. (P 3)
Being Accepted By Others

Participants found it easier to sustain their resolve when they received loving acceptance and encouragement from others. Such acceptance and encouragement, however, did not have to be absolute and/or immediate; the gradual acceptance of their disease by people who previously had ostracized them was also important in sustaining resolve.

Acceptance and encouragement came from a number of people, most notably mothers and close relatives:

My mum gives me emotional support and never expresses disgust in me. She always stands beside me, never lets me down. It encourages me to fight for my life. (P 18)...and...Besides my mother, my aunt and my relatives gave me emotional support and also consoled me. My mind is better. This has encouraged me to confront my problems. (P 13)

Husbands are also important sources of encouragement:

My husband is very kind to me. He supported me in everything. He said that he really loves me and he will look after me. He takes care of me very well. It encourages me. He told me to fight for our life. I feel stronger. (P 8)

Neighbours, too, can be important sources of encouragement:

My neighbours come over and give me emotional support at my house. They said don't worry too much because it is not only me who has got AIDS. There are so many people who have AIDS. They also said to me that not everyone who has AIDS dies from it. Everyone has to die as well. They gave me encouragement. After I talked to them, I felt better emotionally. I will fight this disease. (P 20)

My neighbour knows that my husband died of AIDS. She tried to console me that her husband also died of AIDS. She shared her story with me. She told me don't worry
and try to accept this disease. We felt the same. We have to fight for our life. Don't feel discouraged. (P 5)

In addition, health professionals are important sources of acceptance and support; these include nurses:

I met a nurse (she told her name) who gave me more emotional support at the hospital where my husband was being treated for his AIDS related illness. If I didn't see her at that time, I may have died already. She consoled and talked to me. She tried to advise me on many things. She always came to talk to me. After that, I felt more encouraged. (P 18)

They also include village health workers, of which there are many in each village. Their role is to advise on and treat general health problems including HIV/AIDS. They make home visits to counsel or advise villagers which participants find encouraging:

Some volunteers visit me at my house. They give me encouragement and emotional support. I feel like this disease has not happened only to me. I should fight for my life. (P 6)

Importantly, and as indicated above, immediate and unconditional acceptance is not the only sort of acceptance which encouraged participants to fight for their lives; any degree of acceptance, irrespective of its partiality, served to encourage them:

I think my neighbours accept me better than they used to. I still look healthy and I have no symptoms. They come close. They have a meal with me. They show they don’t discriminate against me. I feel most of them accept me, they treat me normally. (But some dare not come close, I think they are afraid of me..) (P 21)
Someone who used to have nothing to do with me is now getting better...I think they are starting to understand how HIV is transmitted. They are beginning to accept us. (P3)

and I feel satisfied because I am still healthy and do not have any symptoms. I can live with my family in the community. There are no symptoms; no tired feeling, sleeping well and having good mood (laughing)...I live with my child in my house where I sleep and cook rice, but I also eat food at my aunt's house with my sister-in-law, brother, nephew and nieces, about 7-8 people. Eating with my relatives makes me feel good and I can eat happily. Everybody talks to each other. No one is afraid of me like they used to be in the past. (P 4)

Acceptance of their children, too, after a period of rejection, is encouraging:

In the coming session I will take my child to the child care centre. At first they refused to take her because they were afraid she was infected. Now the center's committee has decided to accept my child. It made me feel very happy. (P 3)

This holds true, even after the child has died:

At my daughter's funeral I observed many people came into the house where her coffin was placed. I cried very much. My neighbours came close to me. I felt they weren't scared of me. They brought northern musical instruments to play at my daughter's funeral. They are usually only played at elders’ funerals as a mark of respect. It meant my neighbours loved my daughter. The teacher at the school brought the other students to the funeral...I noticed my neighbours ate the food like normal. (P 21)

**Acting Normally**

Participants tried to act normally, that is, as they did before they became infected, in order both to feel better themselves and encourage 'normal' responses from neighbours. In symbolic interactionist terms, they were attempting to present
themselves as ‘normal’ objects in their object world in order to elicit ‘normal’ reactions (i.e. non-stigmatizing reactions) from others:

When I see them (neighbours) I smile and greet them. I think that if I behave as though I am not infected, I might feel like them...and...I do everything as normal. (P21)

Actively Seeking Support

As noted previously, ‘Hanging In With HIV/AIDS’ was not achieved through passive acceptance of participants’ disease; rather, it was achieved though a range of deliberately chosen activities directed to supporting and sustaining them. These included Going Home to Mother, Deciding to Remarry, Securing Financial Assistance and Joining a PWA Group.

Going Home to Mother

On the death of their first husband, as would be expected in a culture of tight maternal-filial relationships, every participant except one returned to her own village, to live with or close to their mothers:

I went back to my hometown to live with my parents when my husband died. They love me as before (smile), they look after my son. My mum cooks for me. They also give me many supports. They always give me money to buy medicines. (P 22)

I have no income...I have to go back to my hometown to stay with my mother and my son...Mother is old, 80. She is still healthy. She can live by herself. She weaves fabric and sells it once a week. (P 1)

I quit my job, which earned 2,500 baht a month. I go back to my hometown to live with my mum. She is very good to me. She doesn’t despise me. She really loves me. After she knew that I was infected with
AIDS, she took care of me very well. She sold a part of her land and used the money to help me. I don’t have to pay for anything. She also supports me with many things. She always cooks for me and we have meals together. We eat curry from the same dish. She gives me emotional support as well. I feel that my mum is taking better care of me than ever. She always visits me because our houses are close together. She helps me with everything. (P 16)

Deciding To Remarry

Nine of the twenty-four participants decided to remarry after their first husbands died. Four of these participants married men who did not have HIV/AIDS; the rest married men who were also infected with HIV/AIDS. They remarried for a number of reasons. Firstly, they needed someone to understand and share their feelings. Secondly, they wanted someone who was able to take care of them and their children, both emotionally and materially. Thirdly, they wanted to be ‘normal’ i.e. married women.

These needs/desires are typical of rural Thai women who depend on men:

When my daughter got sick and was admitted to hospital I saw the other patients. Their parents looked after them. For myself, I had to care for my daughter on my own. If I have a problem, no one helps me to solve it. That’s why I decided to remarry. I needed someone to take care of me and give me emotional support. (P 21)

I live with my husband. I do not love him but it is good to have someone take care of me. When I am sick he takes care of me well. I think it is impossible to get everything I want. My husband is not a bad man. He works to earn money to spend on the family. Though we don’t love each other very much, we live together. I am satisfied with my life, I live with my husband and my child. I’m not in debt so money is not so important. (P 19)

I married again because I wanted someone to understand and take care of me. My new husband had already been infected with AIDS, and his
previous wife had died of AIDS. He was a good talker. He consoled me and also encouraged me to feel relaxed. I met him at a PWA group. We can also share our feelings that we can’t talk about with others. (P 14)

I thought I should marry him because I can consult him and he has AIDS as well. He will help me to raise my son. I saw that he loved my son. He is very kind. Besides, I feel like others when I can get married. (P 22)

The need to find someone else to depend on led some participants not only to marry men they did not love, but also to marry HIV negative men:

In fact, I didn’t want to marry again. I told my new husband that my last husband had died of AIDS, but he didn’t care. We worked at the same place and he took care of me well. Actually, I don’t love him. I need someone who can help me. I want my life as normal. Before we married he had a blood test which was negative. A doctor advised him to use condoms when we had intercourse, but he didn’t. I didn’t know what to do. He didn’t take the doctor’s advice. He refused to take a blood test. He said he didn’t care. (P 19)

I felt not too sure of how I would cope with my life after my husband died. No one helped me except my parents. I didn’t know what I should do. After my husband had died 3-4 months, another man said that he loved me. His relatives forbade him to marry me because they knew I had AIDS. However, he didn’t change his mind. Before we got married he had a blood test. He was fine. I consulted a doctor who said that I should use condoms. I obeyed the doctor because I didn’t want to infect my husband with HIV. (P 8)

Securing Financial Assistance

Securing Financial Assistance was an important subcategory of ‘Hanging In with HIV/AIDS’ which, in turn, included Accepting Help from Family, Seeking
Appropriate Employment, Seeking Assistance from Government and NGOs and Selling Personal Property. Securing Financial Assistance enabled participants to deal with economic hardship brought on by, among other things, death of breadwinner, loss of employment and costs of medication.

Accepting Help from Family

There is an expectation in rural northern Thai culture that family members will support and assist each other; there is no stigma attached to accepting help from family and participants did this freely:

My son works in the city and he gives me money. My sister also supports me. I have a meal with my parents. I don't buy the food. I work to earn money near my house but not often, because I easily have an allergy and break out in a rash. Sometimes I have problems about money but I have my parents and my sister to support me. (P 15)

Seeking Appropriate Employment

Participants sought appropriate employment for two reasons. Firstly, they had to find some source of income once they had decided to return home to their villages and mothers. Secondly, in rural areas, most people are employed planting crops, paddy farming and in orchard gardening and these all require exposure to sun and insecticides. They also require hard, physical work. PWAs, however, become extremely sensitive to sun and insecticide irritants and are physically incapable of undertaking long hours of hard work.

In light of this, they seek to earn some money doing light work, indoors:
I quit my job. I found another job. I did all kinds of jobs such as sewing, artificial flower making, and tree and flower growing. I have an irregular income but I can survive. I can't ignore any job that I find. I want to work as usual. (P 3)

I used to do gardening and farming. But I quit when I learned that I am infected with HIV. I saw some PWAs work outdoors. They had an allergy to sunlight and some broke out in rashes. Some became ill. I am afraid of headaches. I am also afraid that I will be tired because the sunlight is very hot. My parents do not want me to work hard. They let me work only indoors. My new job is sewing at home. Even though I am infected I can still work, but I am afraid that my health will get worse or I will become sick. (P 9)

I had to quit work gardening at the orchard because it is hard work where I am exposed to a lot of insecticides and the sun. I could not do it. My income decreased, so I helped my sister sew at home to make money for our household. It is not hard work and it is indoors. (P 12)

I try to find jobs, which are not hard work. Now, I sew for money at home. I sew pockets and get 2 baht a piece (pointing to her sewing machine). I don't work outdoors in the sunlight. I don't want to be sick. I cannot do other work but I am good at sewing and happy to do it. It also allows me to earn a living. (P 5)

I want to rear frogs in a pool. I will rear tadpoles because I don't have to use much labour. If I am rearing pigs it is hard work. Rearing tadpoles, I have to feed them only 2 times a day, I may have to clean a pool but I think it is all right. If I can rear tadpoles, I will have income. I don't have any symptom so I think I should work. (P 20)

To some, appropriate employment also provided them with the opportunity for social interaction:

I tried to get a job, being a volunteer in the AIDS network. I went out to visit people 6 times a month. I was paid 10 baht a visit. A little bit of income and it made me happy that I could talk to friends (P 3)
**Seeking Assistance From Government and NGOs**

Both the government and a number of NGOs in Thailand provide funds for HIV/AIDS education programs; they also provide some funds for PWAs. Although this has decreased since the economic down-turn of 1997, some funds are still available:

*There is a Community-Based program in the village. The program was established to help PWAs in this village and close villages. The program has been established for many years. It also helps infected people's children. There is a nursery centre to take care of them. Their parents pay only 10 baht a day. That program will end this year (1998). It is not certain whether this program can be continued or not. The Program's volunteers visit PWAs at their houses, give them mental support and cooperate with other organizations. There are networks between organizations, both NGOs and government...and...I can't earn money, therefore, I decided to borrow 3,000 baht from the Village's fund. I also received support from the government 500 baht a month.* (P 4)

**Selling Personal Property**

When other sources of revenue generation were exhausted, or participants had little access to them, they had little choice but to sacrifice whatever they owned to acquire the funds needed to sustain them. To some (e.g. P10) this meant selling her jewelry, video and tape-recorder. To others, (e.g. P1) mortgaging her land became necessary.

**Joining a PWA Group**

The PWA Group is one of the most important supports which kept participants hanging in. In the PWA Group, participants felt able to share thoughts and feelings they could not share elsewhere; they also felt safe and comfortable with friends who had the same disease. The PWA Group also organized activities which participants enjoyed and from which they earned a little money:
(The PWA Group) I feel release when I talk to my friends who understand me. I feel comfortable. In the group, we are friends. There are more than 10 of us. I can talk with my neighbours but I dare not talk about some things with them. We don’t have to be careful about what we talk about or how we act together. We are all the same...My friends in the PWA Group are the best means of helping me cope. (P 21)

I feel better, like I could keep living because of this group. I have friends to eat with and it gives me a good appetite. At home, I have meals alone and I feel unhappy. When I join this group I feel relaxed. Although since I joined the group I have less time to do my job, sewing, I want to be in the group because it makes me feel comfortable. My friends in the group and the nurse at this hospital understand me. If I have no group, I could not live. (P 10)

Adopting a Healthy Lifestyle

Participants deliberately chose to adopt a healthy lifestyle to assist them to hang in with HIV/AIDS. They did this for two interrelated reasons; firstly, to control/prevent symptoms (one participant to the point of cure) and, secondly, to maintain themselves in the best possible state of health. As part of adopting a healthy lifestyle, participants actively sought medical advice, took traditional herbal medicines, chose a healthy diet and took appropriate exercise and rest.

Seeking Medical Advice

Participants sought medical advice when they became ill and stalwartly took their medications as directed, sometimes for many months:

When I was getting thin and could not eat anything, I went to see the doctor at the hospital. The doctor tried to comfort me. At that time there was a medicine available to prevent lung disease and the
doctor asked me if I wanted take medicine or not. I thought my lungs were fine but I wanted to take medicine to protect my lungs. I did not want to be thin. The doctor told me that I had to take medicine for 9 months and needed to be checked at the hospital. I decided to take the medicine and vitamins to prevent lung disease. I felt healthy and got fat. I can have meals. (laughing) (P 18)

Taking Herbal Medicines

Participants also took herbal medicines which others recommended. They took them to make themselves feel better and some believed that they might be curative:

I took a herbal medicine which had no name and mixed it with honey. I had it for years. I didn't have any symptoms. People who knew me felt pity on me and gave it to me to try. They said it's good like an ambrosia. It made me healthy. I took it once a day before going to bed. (P 2)

I got alternative medicine. It was a bundle. I boiled it and drank it instead of water. I drank it 3 times a day. My father brought it to me. He told me it could cure me. I didn't know what it was. My father said that the seller said that he was also PWA who always dreamed of drugs, which could cure AIDS. And he recovered. He used the drug, which consisted of many kinds of herbs. Then he went to have his blood-tested and his blood was negative. He felt he was healthy and did not have any symptoms. Thus, my father went to find the drug to cure me. I use it everyday. I feel healthy and don't have any symptoms. For example, I can work as usual. Its taste likes water. I think I will always drink it because it causes me no harm. (P 7)
Choosing Healthy Diets

Participants were always careful about what they ate. They preferentially selected foods which were not spicy and/or pickled and avoided taboo foods. They ate the former to stay as healthy as possible and avoided the latter to avoid adverse effects:

I must be careful eating food. I do not eat beef, seafood and pickles. If I eat those foods, I will get headaches, especially pickles. Even its smell makes me tired...I will avoid these foods. Now I’m rather chubby, about 2 kilos more than ever in the last 2 years. I feel I am healthy. I have to take care of myself. Before I became a PWAs, I can eat everything but now I must be careful. (P 14)

I’m afraid of pickles and raw food such as fresh meat. After I knew that I was infected with HIV, I was careful eating food. I’m afraid I will get diarrhea. I try to eat vegetables and fruits. The doctor advised me to avoid pickle. I believe him. I love my life. Sometimes, I wanted to eat relish with papaya salad. I have to make it myself because I don’t want to have diarrhea. I take great care with food and I will always cook for myself. (P 20)

I avoid taboo food such as catfish, bamboo shoot, and seafood... I will get headache. Not comfortable. (P 1)

I feel worse off. For example, frog and fish, I believe that they have some poison on their skins. Some friends eat it and then got worse. (P 21)

I avoid taboo food such as beef and chicken because I’m afraid I will be itchy. (P 15)

Exercising And Resting

It is atypical for northern Thai women to exercise regularly; however, participants in this study exercised regularly and rested regularly to help them ‘hang in’. They believed it kept them healthy, it stimulated the appetite and was fun:
I try to do exercise by jogging everyday about 15 minutes a day. But sometimes I am lazy. I will do jogging around my house. When I do exercise, I feel comfortable and healthy. Perhaps I can't do it...it is hard. Actually I do it irregularly. However, I will. I will take a rest when I feel tired. (P 12)

I do jogging about 5-10 minutes before taking a bath. Sometimes I play jumps with my son. I will do it 2-3 times a week. I exercise with my son. I have fun and stay healthy. After I exercise I can eat more. (P 18)

Making Merit

After participants learned that they were infected with HIV/AIDS they wanted to make merit to help them survive with the disease and stay well. Making merit variously involved praying to images of Buddha (Wai Pra), meditating, going to the temple and helping others as much as they could:

Praying to Images of Buddha

Buddhists normally chant Buddha’s teachings in the Pali language. They believe that reciting these chants before sleeping at night will help to protect them from evil:

I don't worry too much...I pray and chant in worship of Buddha images and ask him to keep me from suffering and danger. I will fight for my life and never give up. (P 1)

Before I go to bed I pray chants and do meditation about 10 minutes every night by inhaling and exhaling according to the monks' teaching. I try to calm down my mind. After that, I feel comfortable. In the past, I did not pray chants everyday. After my husband died, I wanted attachment, so I turned to Buddhism to encourage myself. I have to live with this disease...I think, therefore, I should devote myself to Buddha’s teaching. (P 20)
Meditation

Participants did meditation to calm their minds. Whenever they felt stressed or worried they would try to meditate for about 10-15 minutes. It helped them to calm their minds and to sleep well:

If I start to worry too much, I will try to meditate for about 10-15 minutes. I pray and chant in worship of Buddha images to ask him to protect me and my family. (P 9)

I learned to do meditation when I was a Bramanist nun. If I do meditation, I will feel comfortable. Everyday I try to do it very often and spend time to do it. It is quite hard. Now I do it anytime. I never did it before but after I became a PWA, I did it to comfort myself. I think my mind is important. If I have no courage, I may be down. I have to find something to make my mind calm down. Meditation is useful for me. (P 11)

Going To The Temple

Buddhists go to the temple to make merit by giving food to the monks:

I can’t hope that everyone treats me well. I try to comfort myself and don’t worry too much. I go to the temple to make merit. I offer my food to the monks. I feel better. (P 6)

I go to the temple every holy day and give a feast to the monks. I feel comfortable. I think if I make merit and virtue, my sins will be decreased. Being infected with HIV is like my sin. I can’t overcome it. I go to the temple and I feel better. I am encouraged. (P 16)
Helping Others

Helping others was viewed by participants as an important means of making merit. In addition, however, helping others also made them feel more worthy and valuable persons (which, according to one participant, positively affected her CD4+ count):

My mum's husband died of this disease as well. Blood tests showed that both my mother and I have AIDS. My mother is 48 years old. She told me that we should accept this disease. It is our karma...we may have done a bad thing in a past life and we have to accept the result of our karma in this life. I will do the right thing in this life and in my next life...I will help my friends ...I will look after my daughter. I will help my community as much as I can. (P 24)

I can work in the community. I feel very proud of myself that I am a useful person. I think the community looks at me positively, for example, in my village, I am one of the AIDS Committee. This committee is responsible for helping people with AIDS problems. I work and cooperate with the government and NGOs as well...and ...I feel good about being a useful member of the community, for example, helping with the PWA Group, helping orphans in my village, helping to establish a co-op in my village. I feel very content. I am proud of myself and I think it helps to increase my CD4+ count. I am very happy to help orphans. In the past, I did everything for my daughter, but now I do many things for orphans. I can make merit. I feel happy to do things for others. (P 21)
Summary

Participants in this study were enabled to Survive With HIV/AIDS through two distinct but complementary processes, “Hiding Out” and “Hanging In With HIV/AIDS”. Together, they enabled participants to make the best of their predicament and shield themselves and those close to them from hurtful discrimination.

“Hiding Out” refers to a range of active strategies implemented by participants to protect or shield themselves, their children and their husbands from the actual or expected discrimination associated with HIV/AIDS infection. These included telling lies to employers, schoolteachers and fellow-villagers which is denying, in a range of situations/forums, that they, their husbands and their children were infected. They also told lies to their husbands to protect them from the shock of their (husbands’) own diagnoses; they told their husbands that they were not infected and only had relatively minor ailments.

In addition to telling lies, participants also altered their activities to avoid discrimination. They changed their employment; avoided social contact; shopped in distant villages where their diagnosis was not known; and, arranged for their children to attend school in distant villages, where their diagnosis was either accepted or, again, not known.

They also avoided going to the temple. A further strategy participants implemented in order to ‘Hide Out’ was to keep themselves (that is, their bodies and clothes) clean and conceal any obvious HIV/AIDS related lesions. Being seen to be clean was important as HIV/AIDS is still considered a “dirty” disease in northern Thailand and covering
lesions potentially lessens the degree of discrimination experienced. Participants implemented these “hiding out” strategies because they understood the perspective of the generalized other with respect to HIV/AIDS in rural, northern Thai villages.

“Hanging In” with HIV/AIDS is the process through which participants made the best of their predicament. It involved the very active pursuit of a range of strategies, which enabled participants to live the best life possible, given their disease. “Hanging In” commenced when participants resolved to fight for their lives. Fighting for their lives was easier when they felt themselves accepted, even partially, by family, friends and fellow villagers. Once participants had resolved to fight for their lives, they actively sought socio-emotional and financial support from a variety of sources.

These sources included participants’ mothers and close family members, “new” or existing husbands, government and NGO agencies and, importantly, a PWA Group. Participants believed that they could share their feelings and concerns unreservedly in the PWA Group because they felt totally accepted in it.

In addition to actively seeking socio-emotional and financial support, “Hanging In” also included following a healthy life-style, seeking medical advice, taking herbal medicines and making merit. Following a healthy lifestyle consisted in eating carefully, that is, avoiding any taboo foods or those which potentially were allergenic. It also included regular exercise (which is atypical of ‘normal’ Thai women). Medical advice was actively sought and followed, and most participants also took traditional herbal medicines. They did this to both arrest/slow their disease process and to increase their sense of well-being.
As one would expect of Buddhists, “Hanging In” also included a range of merit-making strategies, that is, a range of strategies to improve the *karma* of participants’ present and future lives. Such merit-making activities included praying and chanting, meditation, going to the temple to feed the monks and assiduously helping others.

“Hanging In With HIV/AIDS” clearly involved the active pursuit of strategies derived from both traditional Thai culture (merit-making, traditional herbal medication, accepting support from family) and Western, modernist ideas (Western medication, exercise, knowledge of the influence of stress on CD4+ count and, in at least one case, insistence that her seronegative husband used condoms for intra-marital sex).

These and other aspects of Hiding Out and Hanging In With HIV/AIDS will be discussed in the context of relevant literature, in Chapter 7.
Chapter Seven

Conclusion and Discussion

Introduction

The purpose of this study was to explore and theorize the experiences of HIV/AIDS of wives and widows in the rural north of Thailand, in terms of the problems/issues they encountered and the processes through which they addressed and managed such problems and issues. More specifically, using grounded theory methodology, it sought to describe and develop a substantive theory which explained how these women understood and dealt with their problems and, by implication, the factors which served to exacerbate or ameliorate them.

This chapter will discuss the findings of the study in the context of contemporary literature and explicate the implications of the findings in terms of recommendations for nursing practice, education, research and for health policy in Thailand more generally. The limitations of the study will also be addressed.

Surviving with HIV/AIDS

The basic social problem experienced by participants in this study was “Surviving with HIV/AIDS (in rural, northern Thailand)”\(^\text{1}\); data revealed a number of inter-related issues which made surviving with HIV/AIDS problematic. These inter-related issues all impeded participants’ ability to undertake the normal activities associated with their role and status as women and, therefore, affected participants’ self esteem (Berger,
1995; Fife & Wright, 2000). Some were attributable to the clinical manifestations of the disease; the majority, however, were directly or indirectly attributable to the cultural designation of HIV/AIDS in rural, northern Thailand. The participants had to deal with rural, northern Thais’ designations of HIV/AIDS and those unfortunates who were infected with it. More specifically, participants were subjected to a range of strategies which, in social interactionist terms, firstly, informed them that they had been designated as highly infectious and “dirty”, which allowed them, secondly, to interpret the “distancing” behaviours of fellow-villagers, employers, etc. and, thirdly, allowed them to plan their own responses to such designations and behaviours.

The findings suggest that participants had four distinct but highly interactive and causally related categories of problems with which to contend in order to survive with HIV/AIDS. These were “The Physical Implications of HIV/AIDS”, “The Psycho-Emotional Implications of HIV/AIDS”, “The Economic Implications of HIV/AIDS” and “The Socio-Cultural Implications of HIV/AIDS”.

These findings are, in general, entirely consistent with related HIV/AIDS contemporary literature (e.g. Chesney & Folkman, 1999; Danziger, 1994; Moneyham et al, 1996; Sherr & Green, 1996) and, indeed, to literature related to other stigmatizing diseases, for example, cancer (Cella & Yellen, 1993; Kelly et al, 1996; Krishnasamy, 1996), mental illness (Farnum, Zipple, Tyrell & Chittinanda, 1999; Ng, 1997; Nicholson, Sweeney & Geller, 1998) and to other infectious diseases e.g. tuberculosis (Kelly, 1999). They are also consistent with much of the literature related to chronic but non-stigmatizing disease, for example, cardiac disease (Moser & Worster, 2000; Theobald, 1997). There are, however, some findings which are particular to this study
and these are culturally derived, that is, they relate to the participants’ status as Thai women, and these will be highlighted in the subsequent discussions.

The Physical Implications of HIV/AIDS

The study included participants who were asymptomatic, early symptomatic and in end-stage disease who suffered a range of HIV/AIDS clinical manifestations. These were important to participants for a range of reasons. Firstly, some clinical manifestations, for example, weakness and fatigue, required participants to curtail their social and work related activities (Chesney & Folkman, 1999). Participants who were too ill, that is, who were weak and cachexic, had neither the will nor the energy to work or socialize (indeed, one participant hardly had the energy to eat). Secondly, because of their observations of other PWAs, participants were aware that certain environmental and dietary influences, for example, sunlight and spicy food, could exacerbate the clinical manifestations of the disease. In light of this, they deliberately avoided potential irritants. Thirdly, the more recognizable HIV/AIDS related manifestations, for example, skin lesions and weight loss, were seen by participants to increase their vulnerability to discriminatory and stigmatizing behaviour. Accordingly, they took steps to conceal such lesions.

In all of these respects, participants’ experiences were similar to other HIV/AIDS populations (Chesney & Folkman, 1999; Danziger, 1994; Koenig & Fauci, 1999; Sherr & Green, 1996; Wright, 1996), to sufferers of other stigmatizing diseases (Cella & Yellen, 1993) and to sufferers of chronic, non-stigmatizing diseases (Moser & Worster, 2000; Theobald, 1997).
Interestingly, no participant complained of or even mentioned gynecological problems. The reasons for this are unclear. It is possible that no participant experienced gynecological problems; it is also possible that they were not considered HIV/AIDS related (and, therefore, of no relevance to this study); it is also possible that they were considered too unimportant to mention (they were not visible and were associated with the lowly status of women); it is also possible that their contribution to disruption of lifestyle was perceived as minimal.

These are, as indicated, merely conjectural. However, if participants were unaware that HIV/AIDS can manifest in gynecological symptoms or that they believed that they were unimportant given that they could only ever affect (inferior) women, then this could be indicative of the influence of culture.

**The Psycho-Emotional Implications of HIV/AIDS**

Findings indicate that the psycho-emotional implications of HIV/AIDS infection included a range of extremely negative emotions associated with grief and loss and, prior to the onset of these, feelings of uncertainly related to their husbands’ and their own diagnoses.

Most of the participants' (20) suspected HIV/AIDS infection when their husbands developed HIV/AIDS related symptoms. Their suspicions were fuelled by their husbands’ use of CSWs, probably for unprotected sex at least some of the time (that is, they had exposing themselves to infection) and because of the extensive media coverage of HIV/AIDS symptoms. However, participants had colluded with their husbands’ “risky” behaviours, either willingly or unwillingly and, because of their
inferior status, felt unable to question or criticize them. In this respect, therefore, they were similar to disempowered women elsewhere, namely: African American women (Raj & Wingood, 1997), low income urban women in the USA (Crumble, Wagstaff, Kelly, Sikkema, Solomon, Anderson et al, 1996), Hispanic women (Pinel, 1996) and Canadian women (Leonard, Plotnikoff & Holz, 1996). In all of these groups, non-use of condoms is associated with the women’s total dependence on their male partners (Pinel, 1996).

In addition, participants recognized that intra-marital use of condoms was considered reflective of lack of trust (even when this was justified). These sentiments, too, are consistent with other low status female partners of HIV/AIDS infected men, for example, African-American (Wingood & Di Clemente, 1998) and Hispanic women (Saul, Dabrowski, Dixon & Moore, 1998) and women who hold ‘traditional’ gender role constructions (Saul et al, 1998).

Interestingly, even though participants were aware that their husbands were frequenting CSWs, were ambivalent with respect to condom use with CSWs and extremely reluctant to use condoms for intra-marital sex, they still felt the shock, denial and anger which typifies the early grief response (Green, 1996: Kubler-Ross, 1987). This was because they were uncertain as to the HIV/AIDS status of their husbands and themselves until the diagnosis had been confirmed.

Participants’ understandable anger changed rapidly to a caring concern for their husbands, especially when they became ill. Every participant stayed with and nursed their husbands through the terminal stages of their disease. They did this for two
reasons. Firstly, because they loved their husbands and, in this respect, behaved similarly to the partners and family members of PWAs from other HIV/AIDS populations, for example, minority women in New York (Baker, Sudit & Litwak, 1998); midlife and older women in California (Wright, Le Blanc & Aneshensel, 1998); the mothers and partners of gay men (Folkman, Chesney, Boccottari, Cooke & Colette, 1992; Nelms, 2000); and, women in southern India (Madhivann, Newmann, Sarin, Kumarasamy, Amalraj, Rogers et al, 2000). Secondly, participants nursed their husbands out of kreuang jai, that is, because it was their duty as wives. The influence of Thai culture, therefore, is clearly operational in participants’ responses.

Participants’ initial reactions of shock, denial and anger were followed variously by continuing anguish, what other authors term chronic sadness or depression, hopelessness and, sometimes, suicidal ideation and even attempt (Munjas, Oliver & Luna, 1998; Rabkin & Ramien, 1995; Sangchart, 1998). These responses, as previously indicated, are typical of anyone who is confronting loss (Kubler-Ross, 1987; Munjas, Oliver & Luna, 1998). The strength of such feelings was a function of the extent of actual or expected (feared) loss.

Participants experienced a range of fears. They feared what the disease process entailed for them by way of suffering and loss of function (Bartlett & Finkbeiner, 1996). They feared that their children would or had contract(ed) the disease from them (Chesney & Folkman, 1999). They feared for their children’s future, that is, what would happen to them once they became incapacitated or died (Richardson, 1989). They also feared discriminatory behaviour from family, friends and fellow-villagers (Munjas, Oliver & Luna, 1998). In all of these respects their responses are consistent
with those of people who suffer from any incurable, infectious and/or stigmatizing disease (Kelly, 1999; Ip & Mackenzie, 1998; Moser & Worster 2000; Sherr, 1995; Theobald, 1997).

The Economic Implications of HIV/AIDS

There were many economic ramifications of HIV/AIDS infection for study participants. Firstly, and as noted above, the physical manifestations of the disease, either present or potential in herself and/or her husband, required a change or cessation of employment (Pitayanon, Kogsin & Janjareon, 1994). This led to loss of earnings. Secondly, regular screening programs in some Thai industries led to both involuntary resignation (Ritchie 1998), where infected employees are asked to resign (because employers cannot afford the costs of treatment) and voluntary resignation, where employees elect to resign before their diagnoses are discovered (to avoid ostracism from workplace colleagues). Thirdly, the loss of the earnings of the family’s primary bread-winner, that is, the husband, (due to illness, voluntary and involuntary resignation and death) left some families in financial hardship. This is due in part to the salary differentials, contingent upon gender status differentials, which still operate in Thailand. Fourthly, the relatively inferior status of women lead to at least one participant losing her estate to her deceased husband’s family. Fifthly, the costs of antiretroviral and other medications exhausted the financial resources of some families. The economic impact of HIV/AIDS on participants and their families, therefore, could be considerable and accumulative (Friedland, Renwick & McColl, 1996; Manopaiboon et al, 1997). Of course, people suffering from any serious, chronic and/or stigmatizing disease can experience economic hardship (Cella & Yellen, 1993; Glosier, 1998; Theobald, 1997); however, the socio-cultural and political context in which people find
themselves largely determines the degree of hardship they experience (Pothisiri, Tangcharoensathien, Lertiendumrong, Kasemsup & Hanvoravongchai, 1998). This was clearly the case for participants in this study.

To begin with, participants clearly preferred the risk of economic hardship to the discrimination that the discovery of their diagnoses entailed. This was because HIV/AIDS was designated more shameful than poverty in rural, northern Thailand. In addition and as already noted, the salary differentials between women and men and the loss of widows’ estates were directly attributable to gender status differentials. Thirdly, the inability or failure of the Thai government to fund or subsidize HIV/AIDS treatment and the requirement for regular screening programs in some industries is clearly a function of differential political priorities (Pothisiri et al, 1998).

These and related socio-cultural and political factors will need to be taken into account when considering appropriate health policy and therapeutic interventions. Accordingly, they will be addressed again, below.

**The Socio-Cultural Implications of HIV/AIDS**

HIV/AIDS is construed as incurable, highly infectious and, because it is transmitted through “risky” behaviours (sex and intravenous drug use), as “dirty” in the rural north of Thailand. For these reasons, people who were not infected with HIV/AIDS sought to minimize the risk of infection by distancing themselves socially (by “looking at” PWAs in a certain pointed way) and physically (by staying physically distant from PWAs and anything of theirs which could be a source of infection). The result of these two strategies was a curtailment of the normal role activities of participants, that is,
those they would normally undertake as women. The degree of disruption was related to the obviousness of participants’ HIV/AIDS status (skin lesions, weight loss), the amount of correct HIV/AIDS related information villagers possessed and the length of time from learning of diagnosis. Some fellow-villagers gradually came to accept, or partially accept, PWAs in this study.

“Being Looked At” and “Being Kept At A Distance” are typically experienced by people suffering from stigmatizing and/or infectious disease, for example, people with tuberculosis (Kelly, 1999), cancer, mental illness (Kellinghaus, Eikelmann, Ohmann & Reker, 1999; Trauer, Duckmanton & Chiv, 1998) as well as other HIV/AIDS populations (Berger, 1995; Bunting, 1996; Hackl, Somlai, Kelly & Kalichman, 1997; Moneyham et al, 1996; Sowell, Lowenstein, Moneyham, Demi, Mizuno & Seals, 1997).

“Being Looked At” and “Being Kept At A Distance” occurred in two distinct but related contexts; they occurred on an everyday basis, for example, when fellow-villagers refused to eat with PWAs or allow their children to attend school with the children of PWAs, and they occurred episodically, at culturally significant events, for example, weddings and funerals. Participants were thus stripped of important components of their roles as kulasaatrii and mae, roles from which their status and self esteem were derived (Berger, 1995). Role changes are also known to affect the self-esteem of people with other diseases (Cella & Yellen, 1993, Fife & Wright, 2000; Theobald, 1997; Wright, Gronfein & Owens, 2000).
“Being Kept At A Distance” is consistent with other HIV/AIDS related literature. PWAs typically experience abandonment and social rejection (Fife & Wright, 2000; Sherr & Green, 1993; Thampanichawat, 1999; Weitz, 1990). Non-infected people refuse to share food or even bathrooms with PWAs (Songwathana, 1998; Weitz, 1990); the equipment and utensils they use are frequently discarded or disinfected by non-infected people (Limanonda & Nokyoongthong, 1995; Sherr & Green, 1993; Songwathana, 1998); and, they are frequently dismissed from paid employment (Chesney & Folkman, 1999; Weitz, 1990).

Family members of participants were also kept at a distance; this, too, is consistent with contemporary HIV/AIDS literature (Fordham, 1993; Gewirtz & Gossart-Walker, 2000; Gilman, 1999; Powell-Cope & Brown, 1992) where the children of PWAs are frequently dismissed from school (Chesney & Folkman, 1999). The literature, however, tends to emphasize the disruption of everyday role activities rather than both everyday and episodic cultural events. The influence of traditional Thai culture is evident in the importance participants' assigned to culturally significant events; such events provide welcome opportunities for whole villages to congregate, celebrate, console, etc. Little wonder that participants’ inability to contribute to such events caused them acute distress.

These, then, were the problems with which participants in this study had to deal. Clearly, most of their problems were culturally derived. The data suggest that participants dealt with the problem of surviving with HIV/AIDS through two distinct but complementary processes, “Hiding Out With HIV/AIDS (in rural, northern Thailand)” and “Hanging In With HIV/AIDS”. Hiding Out was the process through
which participants concealed or attempted to conceal their disease and Hanging In was the process through which they made, or attempted to make, the best of their predicament.

The influence of culture is evident in the strategies participants implemented, particularly with respect to hanging in with HIV/AIDS. What this implies, rather obviously, is that traditional Thai culture is both the major source of participants’ HIV/AIDS related problems and the major source of their solutions to such problems.

**Hiding Out With HIV/AIDS (in rural, northern Thailand)**

“Hiding Out” referred to any active strategies participants implemented to protect themselves, their husbands and their children from the discrimination associated with HIV/AIDS infection. “Hiding Out” was a mirror-image of “Being Kept At A Distance” and it included both telling lies, that is, denying infection, and altering their activities in order to conceal their own or other family members’ diagnoses.

The HIV/AIDS-related literature suggests that disclosure of diagnoses can be an important issue for PWAs and their families (Poindexter & Linsk, 1999; Powell-Cope & Brown, 1992; Sowell et al, 1997) and the literature regarding other stigmatizing diseases, for example, tuberculosis (Kelly, 1999) supports this. However, in this study, there was no evidence of any ambivalence with respect to disclosure; participants unanimously chose non-disclosure (hence their lying and change of activities) for fear of serious discrimination. Whether this was related to self stigmatization (cf. Moneyham et al, 1996) is not clear from the data; it is consistent, however, with other HIV/AIDS research in Thailand (Tangmunkongvorakul, Celentano, Burke, De Boer,

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Wongpan & Suriyanon, 1999). There was one aspect of telling lies that was of particular interest in this study and that was the tendency to lie to husbands about their (husbands') diagnoses in order to protect them from the horror of the truth. This behaviour appeared related to the tendency of participants to nurse the husbands who had infected them through their terminal illnesses. Participants were behaving exactly as would be expected of a kulasatrii and mae; they acted out of love but also out of kreng jai (Chaiprasit, 1994).

Similar behaviour, that is, concealing the diagnosis from the PWA and nursing him or her even though s/he has clearly been the one who infected her/his partner has been observed in gay men (Hays, McKusick, Pollack, Hilliard, Hoff & Coates, 1993) and other women with HIV/AIDS (Thampanichawat, 1999). It has also been observed in care-givers of people with other stigmatizing diseases, e.g. mental illness (Ip & Mackenzie, 1998) and other incurable diseases, for example, cancer (Chunlestskul, 1998) but, of course, the patients in these situations have not infected the care-givers.

The data with respect to the participants protecting themselves from social stigma was particularly poignant. Participants selectively withdrew from the social activities, which were normally part of their roles as women, such as cooking at culturally significant events, to the point that some isolated themselves almost totally. They also took the trouble to shop in distant villages where their diagnoses were not known and to resign or change employment to avoid disclosure and discrimination. Similar behaviour has been reported with respect to other PWAs. For example, gay men (Hays et al, 1993) and other infected women (Sowell et al, 1997), including African women (Dossou, 1998).
“Being Clean and Covered” was another strategy participants used to conceal their diagnoses and protect themselves from stigma. Participants took great care to present themselves publicly with clean bodies and in clean clothes to counteract the social construction of HIV/AIDS as a “dirty” disease. They also ensured that any obvious HIV/AIDS related lesions were covered because levels of discrimination were associated with the easily-recognized or well-known HIV/AIDS symptoms. In both respects, participants behaved as other PWAs do (Weitz, 1990) and as cancer suffers used to do, when cancer was considered a “dirty” disease (Moneyham et al, 1996).

(There was no evidence in the data that participants revealed their diagnoses to explain their unusual behaviour or attempted to educate others with respect to the biological basis of the disease; both of these strategies have been used by other PWA populations to assist them to survive with HIV/AIDS (cf. Weitz, 1990)).

**Hanging In With HIV/AIDS (in rural, northern Thailand)**

“Hanging In With HIV/AIDS” was found to be the second major social process through which participants survived with HIV/AIDS; it was complementary to but mutually exclusive from “Hiding Out” and it involved a number of strategies which assisted participants to make the best of their predicament. Many of these strategies were culturally derived.

Hanging In, as a process, did not begin until participants had recovered from the shock of learning their diagnoses; it began when participants resolved to fight for their lives. Participants resolved to fight for their lives because they compared their own situation
with those of others, and felt favourably advantaged; because they “realized” that everyone must die; and for those who had children, because of the desire to see them grow and flourish (Gaskins & Brown, 1997; Wattanaphilin, 1996). In these respects, participants were similar to other HIV/AIDS infected women (Thampaichawat, 1999).

Having resolved to fight for their lives, participants found it easier to sustain their resolve when they felt that they were accepted by others and when they themselves acted “normally”; they also actively sought support to assist them to fight for their lives.

Acceptance and encouragement was given participants by a number of people, most notably their mothers, husbands and family members; this would be expected in traditional Thai culture. It was also important for participants to be accepted by neighbours, friends and health professionals. However, acceptance did not have to be immediate or unconditional; even gradual and partial acceptance was considered important.

These findings concerning acceptance are consistent with the contemporary HIV/AIDS related literature (Bor, 1993; Greenfeld, 1989) including that relating to Thailand (Gangonta, 1996; Jurawat, 1997; Kong spuriyavanin, 1997; Thongkanrord, 1999).

Participants also found it energizing to act normally, that is, as they did before they became infected. It was suggested that presenting themselves as ‘normal’ was a strategy to elicit ‘normal’, that is, non-stigmatizing behaviours from others. This
strategy is precisely that used by gay men with HIV/AIDS to convince others that they are still fully functioning human beings (Barroso, 1997; Weitz, 1990).

Data demonstrated clearly that hanging in did not involve passive acceptance of participants' HIV/AIDS diagnoses; it involved a range of strategies to actively seek support from a variety of sources. These included going home to mother, deciding to remarry and securing financial assistance.

Returning to their home villages to live with or close to their mothers is typical of northern Thai women who lose their husbands and/or their jobs. It would be expected, therefore, that even when HIV/AIDS was the cause of loss of husband and/or employment, participants would go home to mother. In this respect, traditional Thai culture clearly assisted participants to hang in. Such assistance may be denied other PWAs, particularly gay men and IVDUs (Daniel, Lupo, Vardonin, Yust & Burke, 1991; Hays, Catania, McKusick & Coates, 1990; Kissinger, Niccolai, Farley, Maher & Petermann, 1999; Turner, Hays & Coates, 1993).

Deciding to remarry was a strategy which many participants pursued. They decided to remarry to acquire assistance with child rearing and expenses, to be cared for and nursed when sick and, to feel 'normal'. It appears, therefore, that this strategy, too, is culturally derived. Thai women find status in their role of kulasatrii and mae and it is not acceptable for women to live 'separate' lives from men.

Traditional Thai culture also assisted participants to secure financial assistance; there is an expectation in rural Thai families in the north that family members will support and
help each other. There is no stigma attached to accepting help from family and participants did this freely. Again, this type of assistance may be denied some other PWAs especially gay men and IVDUs (Daniel et al, 1991; Smith & Rapkin, 1996; Turner, Hays & Coates, 1993).

Participants adopted three further strategies to assist them to secure financial assistance; these were ‘Seeking Appropriate Employment’, ‘Seeking Assistance from Government and NGOs’ and ‘Selling Personal Property’.

Participants sought appropriate employment for two reasons; firstly, to find some source of income once they had gone home to mother and, secondly, to avoid exposure to long hours of hard work, sunlight and irritant insecticides. In terms of seeking appropriate employment, inability to undertake long hours of physical work and sensitivity to environmental irritants participants were similar to other PWAs (Nantachaipan, 1996; Sherr, 1993). They differed only insofar as they could elect to return to home villages and mothers.

Participants also sought financial assistance from government and NGOs; acquiring assistance from these sources, however, has become problematic due to public health cut-backs (Pothisiri et al, 1998) and is likely to remain problematic as long as current policy priorities persist.

Finally, some participants were forced, in the last resort, to sell personal property to raise cash for food, schooling and medication. They had this in common with other
PWAs populations (Fletcher, 1996; Sherr, 1993) where health and welfare services are not government funded.

A further strategy which participants actively pursued to assist them to ‘Hang In’ was to join a PWA Group. Just like other PWA populations, participants found that the PWA Group was the only place where they could share their feelings and experiences unreservedly with others (Barough, 1992; Friedland, Renwick & McColl, 1996; Gongonta, 1996; Natpratan, 1998; Senaratana, Limtragool, Suwanprapisa, Potjanamart & Tapinta, 1999). Yet another was ‘Adopting A Healthy Lifestyle’; they adopted healthy lifestyles to control and prevent symptoms and to maintain themselves in the best possible state of health. Accordingly, they sought medical advice, took traditional herbal medicines, ate healthy diets and exercised regularly. In all these respects, they were similar to other PWAs (Barroso, 1997; Jundee, 1997; Natpratan, 1998; Songwathana, 1998). Interestingly, the taking of regular exercise is not typical of northern Thai women; exercising regularly, therefore, is illustrative of participants’ active pursuit of the best possible state of health.

The final major subcategory of Hanging In was identified as ‘Making Merit’; clearly, this particular strategy is deeply rooted in traditional Thai culture. Participants made merit to improve their karma in this life (to survive with the disease and stay well) and in their next lives. Making merit consisted in praying, meditating, attending temple ceremonies and feeding the monks and in assiduously trying to help others (Gaskins & Brown, 1997; Senaratana et al, 1999; Songwathana, 1998). All of these activities helped participants to ease their minds and to feel positive about themselves and this is
consistent with other research findings related to HIV/AIDS in Thailand (Tansriratanawong, 1998).

The Physical and Psychosocial Implications of HIV/AIDS Infection for Rural, Northern Thai Wives and Widows

It is clear from the data, and from related contemporary HIV/AIDS literature, that the psychosocial implications of HIV/AIDS are more problematic and potentially more painful than the physical implications (Ragsdale & Morrow, 1990; Sherr et al, 1993) and, indeed, some of the physical implications become more pressing because of their psychosocial ramifications e.g. lesions, loss of employment, etc. This is not to deny that HIV/AIDS is seriously and progressively debilitating, for clearly it is. It is, rather, merely to recognize that, from a PWA perspective, the psychosocial implications of the disease are typically the most problematic and painful. This is also true for people suffering other stigmatizing diseases, e.g. mental illness (Crisp, Gelder, Rix, Meltzer & Rowlands, 2000). This needs to be borne in mind by health care professionals who provide care to PWAs and policy brokers who develop health care policy in Thailand, as well as elsewhere.

It is also clear from the data that the psychosocial tasks which HIV/AIDS infected Thai wives and widows needed to address to survive with HIV/AIDS were broadly similar to those of other PWA populations. Clearly, participants in this study had to overcome their initial fears, modify their lifestyles, redefine relationships, re-evaluate the meaning of their lives and adjust to physical and social limitations. Rather more positively, they had to develop both emotion-focused coping strategies (e.g. making merit, joining PWA Group) and problem-focused coping strategies (e.g. taking
children to distant schools, electing to change employment) to maintain their physical and emotional health (Chesney & Folkman, 1999). These strategies, of course, could be considered useful in re-establishing *kreng jai*; there was no evidence in the data, however, that this was what participants were primarily concerned to achieve (cf Bechtel & Apakupakul, 1999).

In addition, it is clear from the data that the majority of participants’ HIV/AIDS related problems, and their potential solutions, are culturally derived (and these have been explained in social interactionist terms). Any recommendations, therefore, at policy and practice (clinical, education and research) seriously aimed to improve the care and well-being of HIV/AIDS infected rural, northern Thai wives and widows, must be sensitive to this culture.

**Recommendations For HIV/AIDS Health Policy In Thailand**

When developing recommendations for health policy in Thailand, a number of important and inter-relating factors should be considered. These include the Thai government’s HIV/AIDS funding priorities, the predominant mode of infection in Thailand, the differential status of women and men and the seriously stigmatizing nature of the disease.
The Thai Government’s HIV/AIDS Funding Priorities and the Predominant Mode of Infection in Thailand

The economic downturn in Thailand in 1996-7 lead to a 33% reduction, in real terms, in the national HIV/AIDS budget (Pothisiri et al, 1998) and despite policy intentions to increase the allocation to social and psychological services, antiretroviral medication, medication for opportunistic infection and donor blood screening continue to absorb the bulk of the budget (Pothisiri et al, 1998). This is despite the fact that the total HIV/AIDS budget would only fund 18% of the costs of treating opportunistic infections for the one third of all Thailand’s AIDS patients who manifest them at any one time (Pothisiri et al, 1998). Two other policy decisions are worthy of note: the first is that funds to prevent vertical transmission have been reduced by 74% (despite the increase in ‘fifth wave’ infections) and, the second is that condom distribution has been reduced by 5% (10 million condoms per annum). The government considered that CSWs could purchase condoms for use with clients, despite the cost per condom absorbing 14% of their earnings per client. Sexual behaviour change is key to the control of the HIV/AIDS epidemic in Thailand and the government recognized this in its 1997 ‘100% Condom Use Campaign”. To reduce the distribution of condoms at the same time as advocating 100% condom use could be seen to be sending mixed messages to the Thai people.

Given that infection in Thailand is currently overwhelmingly through unprotected heterosexual intercourse (vaginal and/or anal) and that the Thai epidemic is currently in its fifth wave (i.e. through vertical transmission) these policy decisions appear unintelligible and require revision.
Intact condoms prevent the infection of CSWs, both direct and indirect, they prevent the infection of the clients of CSWs and they also prevent the infection of the wives of infected clients (and, by implication, the infection of the children of clients' wives). Given this, it would seem reasonable to ensure that resources are provided to enable access to condoms and, more importantly, to educate (convince) CSWs and Thai men to access and use them for every sexual encounter. This would be a more effective strategy to control the Thai epidemic than funding antiretrovirals and opportunistic infection medication on a hopelessly inadequate basis.

CSWs remain an important reservoir for HIV/AIDS infection in Thailand; this implies that their activities and their health status should be monitored on a regular basis. This is easier for CSWs working in or through brothels; Thai men should be encouraged, therefore, always to use direct rather than indirect CSWs (if they insist on using CSWs at all). Appropriate education programs should be targeted to schools, universities, military establishments and any other locations where men and boys congregate. Importantly, too, they should be targeted to CSWs. In addition, condoms should be made freely available in brothels and in places where men and boys gather.

The consideration of some sort of policy with respect to drunkenness and brothel-based commercial sex might also be of value since drunkenness is associated with non-use of condoms. Simplistic, blanket policies should be avoided, however; prohibitions related to brothel-based commercial sex could lead to an increase in the use of indirect sex workers (who are more willing to engage in unprotected sex and who are, therefore, at higher risk of infection).
In terms of changing Thai men's sexual behaviour it might also be useful to mount an extensive media campaign, which portrays unprotected sex with CSWs and casual girlfriends not as manly but as simply stupid. Observing family members and friends die of HIV/AIDS in increasing numbers may serve to reinforce its stupidity. Similarly, a campaign which suggests that it is manly to protect innocent wives and children from the risk of infection through intra-marital use of condoms might also be useful. It would be consistent with Thai men’s adoption of ‘Western’ chivalry where women are viewed as weaker and in need of protection.

From a psychosocial perspective, the reduction of funding to PWAs Groups could have serious deleterious effects on the well-being of many Thai PWAs. This is likely to become increasingly true as large numbers of people from the same family die of HIV/AIDS. There is overwhelming evidence that strong social support networks are critical to PWA well-being (Leserman et al, 2000; Sandstrom, 1996); this would suggest that support to PWA Groups should be increased, at least to their pre-1997 levels.

**The Differential Status of Women and Men in Thailand**

It has been noted frequently throughout this thesis that women in Thailand are seen as inferior to men and that this status differential is rooted in Theravada Buddhism and ancient mythology.

Buddhism is particularly powerful in sustaining this gender differential. Firstly, women are denied ordination; this means that their access to free, continuing educational opportunity and redemptive merit-making are seriously curtailed.
Secondly, and, related to this, women are denied access to well-remunerated employment and must make merit by, among other things, being *kulasatrii* and *mae* and *bunkhun* (supporting parents and siblings).

The employment opportunities for young women from poor rural families, who have had little formal education, have decreased since the economic downturn of 1996-7; opportunities to work in the construction and manufacturing industries have decreased. Many young women from poor rural families, therefore, turn to work as CSWs in order to earn a living and express *bunkhun*. This is easier for young women from the north of Thai where work as a CSW does not carry the same stigma as in other provinces.

It would be simplistic to suggest that by providing free, continuing education for young women from poor rural families they would be able to access well-remunerated employment (and still express *bunkhun*). The plight of poor rural families is such that they require *bunkhun* sooner rather than later (especially if they have members who are HIV/AIDS infected) and opportunities to top corporate and public sector positions are restricted to men. In addition, men systematically earn more than women. It would be more realistic, therefore, in the short-term at least, to ensure that young women from the rural north who temporarily work in brothels are educated with respect to condoms and have free access to them.

Buddhism also makes it difficult to address the *kulasatrii*’s vulnerability to infection; the *kulasatrii* defers in all things to her husband and, typically, he refuses to use a condom for intra-marital sex. It is unrealistic to expect the *kulasatrii* to become more
assertive regarding her sexual health in the short-term; in the longer-term, however, continual exposure to non-sensationalized HIV/AIDS education and 'Western' perspectives on sexual health may make a difference. The migration of young people from rural areas to cities could well expedite this cultural change; after all, increasing numbers of young Thai women are already engaging in pre-marital sex (Nelson, Celentano, Eiumtrakul, Hoover, Beyrer, Suprasert et al, 1996) and the status markers for both sexes in urban culture have changed to education and wealth (Mueke, 1984) suggesting that the traditional image of the kulasatrii may not have the appeal that it once did, at least not for young Thais.

In the shorter-term, however, it may be possible to enlist the assistance of Theravada Buddhism to protect the kulasatrii from infection. To engage in sexual activities which result in sorrow violates the Third Buddhist Precept; abbots, monks and male village elders could do much to exhort Thai men to refrain from unprotected sex when infection (sorrow) is any kind of risk. There are indications that abbots, at least, are willing to take on such a role but consider that they require more detailed HIV/AIDS education (Parrittrakadee, 1994).

The Stigma of HIV/AIDS

The findings of this study and the international literature on HIV/AIDS demonstrate overwhelmingly that the majority of the problems PWAs face are a result of the stigmatizing nature of the disease; what this obviously implies, therefore, is that attempts should be made to de-stigmatize the disease if the lives of PWAs are to be improved. In addition, and with particular respect to PWAs in rural, northern Thailand, this would enable them to capitalize more fully on the advantages their
culture presents, that is, the expectation that they will go home to mother, close family will support them financially and emotionally, they will re-marry and make merit.

De-stigmatizing HIV/AIDS will not be an easy task; the disease is considered ‘dirty’ because of its association with sex and drugs and its routes of transmission may not be fully understood by relatively poorly educated Thais, in particular.

Educating all Thai people with respect to the transmissibility of HIV/AIDS is clearly an urgent priority. This could become a component of any HIV/AIDS media campaign; there are already indications that appropriate education programs decrease the use of CSWs and STD infection and increase the use of condoms, in young Thai men (Nelson 1996). In addition, demonstrating that innocent kulasatrii and children are becoming infected in increasing numbers (and possibly showing the ravages of the disease in both these groups) may assist to convince Thais that HIV/AIDS is not a ‘dirty’ disease; it is merely a disease which more and more people in Thailand are contracting.

**Recommendations for Nursing Practice**

The findings of this study demonstrate that HIV/AIDS infected northern Thai wives and widows survive with HIV/AIDS by “Hiding Out” and “Hanging In” with the disease; clearly, therefore, therapeutic nursing practice with respect to PWAs should seek to support these processes.

In terms of Hiding Out, nurses should respect the disclosure wishes of all PWAs and perhaps advise PWAs with respect to covering lesions and obvious weight loss. They
should also empathize fully with PWAs’ attempts to hide-out; taking the trouble to arrange schooling in distant villages, for example, is often made easier knowing that “someone” understands.

In terms of Hanging In, nurses can be more obviously constructive. To begin with, being accepted by others is critical to hanging in, and this includes health professionals (as this study demonstrates). “Caring” should not be left to families (indeed, many PWAs in future will not have families); caring should also be the responsibility of health professionals, including nurses. Nurses should always treat PWAs as ‘normal’ people, taking due (but subtle) regard for their own protection when dealing with potentially infected material. This study and the international literature suggest that being treated as ‘normal’ is the most important motivation to hang in. In addition, nurses can encourage newly diagnosed PWAs, in particular, by telling them that people who ostracize them now may come to accept them, if only partially, given time.

Nurses can also encourage PWAs to act “normally” not only by treating them as ‘normal’ but also by suggesting that ‘normal’ behaviour will tend to elicit ‘normal’ that is, non-stigmatizing behaviour from others.

It is important to recognize that nurses have a duty to educate the public with respect to HIV/AIDS for, at the very least, education will help to destigmatise the disease and possibly prevent infection. Every opportunity to provide non-sensational and accurate information on HIV/AIDS and how infection may be prevented should be seized.
Recommendations for Nursing Education

Pre-registration nursing education should ensure that all nurses are equipped with a sound knowledge of HIV/AIDS, its prevalence, epidemiology, treatment and nursing care. It should aim to equip nurses with the knowledge and skill to enable them to protect the personhood of HIV/AIDS infected people, whenever they contact them, to advocate on the behalf of all PWAs and educate the public (see above) and to protect themselves from possible infection.

Graduate nurses’ education should focus on the specialist treatment and care of different populations of PWAs, that is, prevention, treatment and ongoing support.

Recommendations for Nursing Research

Recommendations for nursing research arise directly from the finding of this study, arise indirectly from it and include both descriptive / explanatory and interventionist studies.

The focus of this study has been HIV/AIDS infected wives and widows in the rural north of Thailand, none of whom complained of gynecological problems. This finding is inconsistent with the international HIV/AIDS literature and should usefully be investigated.

Participants in the study were wives and widows from the rural north, who had very limited formal education and were of relatively low socio-economic status. The substantive theory produced, which is securely grounded in the data and informed by a social interactionist perspective and which was affirmed by participants as consistent
with their understandings and experiences, provides a credible explanation of the way in which this group of people managed to survive with HIV/AIDS. It provides new insights into the perceptions and experiences of this group of people and the factor, which serve to exacerbate and/or ameliorate their HIV/AIDS related problems. Clearly, therefore, research into the experience of other PWA populations is required. The experiences of Thai women living in cities and those of higher socio-economic status and, indeed, Thai men (urban, rural, high and low socio-economic status) should also be investigated. The problems which beset these groups of people, and their appropriate solutions, may well differ from those of this study’s participants.

The results of the fourth and fifth wave of the Thai epidemic together with the Thai government’s current policy of reducing funding to prevent vertical transmission are likely to include increasing numbers of sole-surviving family members and orphaned children. Given the criticality of strong social support networks to PWA well-being, therefore, the experiences and needs of these PWAs warrant investigation. In addition, comparative research into the experiences and needs of infected children with parents and those who are orphaned could usefully be undertaken.

Another important group of PWAs whose experiences and needs require investigation are CSWs and, again, comparative research involving different Thai provinces (with different attitudes to CSWs) would be useful.

The findings of this study and the international literature suggest that “blanket” education campaigns targeted and tailored to particular groups would be more cost-effective in controlling the Thai epidemic than the (inadequate) funding of
antiretroviral medication and the (inadequate) treatment of opportunistic infections. This suggestion requires empirical investigation (although the problems of reporting could make it extremely difficult).

Interventionist/empowering studies, it has been suggested, are also required; these would be consistent with Thai government policy rhetoric (Pothisiri et al 1998). Interventionist research could usefully include prevention and therapy/support.

In terms of prevention, participatory action research with groups of vulnerable young men, groups of vulnerable young women and groups of CSWs might be useful in designing culturally acceptable strategies to eliminate or at least reduce the incidence of unprotected sex. Similarly, but in terms of therapy/support, participatory action research groups could be established in both urban and rural locations where there are large numbers of PWAs, to deal with pressing local problems in culturally acceptable ways.

**Limitations of the study**

This study was designed to be exploratory/descriptive and to produce a substantive theory of the experiences of HIV/AIDS infected wives and widows in the rural north of Thailand. Consistent with grounded theory principles, the theory reflects the experiences of the study population and generalisability is not claimed. In addition, as with all qualitative designs, much of the analysis is a product of the researcher’s mental activity and the naming of categories occurred as a result of the researcher’s own use of words and language. This is of particular salience to this study, where the researcher was required to translate from one language and conceptual scheme to
another and where linguistic equivalence was not always available. While dictionary definitions were used to assist in the selection of words and transcripts have been used to illustrate meaning and derivation of meaning, limitations that result from the human element of this process are acknowledged.

A further limitation, which has been mentioned previously, relates to the researcher's own *kreng jai*. It is possible that some data was not enriched because of the researcher's concern not to offend or embarrass participants.
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Appendix One

First Interview Guidelines

Participant Number..................Date..................
Age..................
Marital status...........
Occupation...............Income (baht per month)..............
Education..............
Number of children.............Age of children..............
Number of people in household...........

1. Opening Question
   1.1. I know that you have been diagnosed with HIV/AIDS; would you like to tell me what it is like living with HIV/AIDS?

2. Diagnosis of HIV/AIDS
   2.1 What led to your diagnosis?
      (Probes: suspicions-husband’s symptoms, husband’s ‘risk’ behaviours blood test)

3. Reaction to Diagnosis
   3.1. How did you feel when you learned you had HIV/AIDS?
      (Probes: immediately; after a while; shock, denial, anger, fear, depression, suicidal tendency)
   3.2. Why did you feel this way?
   3.3. How do you feel about it now?
   3.4. Why?
4. Effects of HIV/AIDS on Lifestyle

4.1. Has HIV/AIDS had any effect on your life?

4.2. Can you give me some examples?

(Probes: physical symptoms
psychosocial role fulfillment
- activity curtailment (e.g., employment)
- isolation
- relationships)

4.3. Were/are you able to do anything about this?

4.4. How do you feel about these effects on your life?

4.5. Have the effects of HIV/AIDS on your life changed during the period since diagnosis?

4.6. Why do you think they have changed?

4.7. How do you feel about this?

4.8. How do you deal with such changes?)

5. Coping with HIV/AIDS

5.1. Does anything help you cope with HIV/AIDS?

5.2. Does anything make you feel better?

5.3. Can you give me some examples?

5.4. What is the worst thing about living with HIV/AIDS?

5.5. Why?

5.6. Is there anything you can you about it?

5.7. How do you feel about this?
(Probes: if your sister were diagnosed with HIV/AIDS, how would you treat her? Why?)

How would you want the villagers treat her? Why?

How would she feel about this? What would you want for her? Why?)

6. Closing Question

6.1. Is there anything else you would like to tell me about living with HIV/AIDS?

6.2. Is there anything else you think it would be useful for me to know?