By the turn of the millennium, HIV had infected nearly one million people in Thailand. A large number of support groups now exist throughout the country. These groups have emerged as the primary forum through which having HIV is negotiated and normalized in Thai society. This is done by allowing members to publicly refashion their sense of self and its appropriate place in the world. However, the moral and social space created by support groups is not without its own structuring principles. The discursive strategies that shape support groups are embedded within local moral economies and frameworks of meaning. Gender and social identity are significant factors that influence the benefits to be gained from belonging. To date, women markedly outnumber men in most groups, and many members regard masculinity as a constraining factor on male participation. Within support groups, unwillingness to join is considered one reason for the perception that men with HIV seem to die sooner than do women with HIV. Clinically true or not, this belief has major ramifications.

Key Words: HIV/AIDS; Thailand; support groups; gender; stigma; social transformation

In our community life, members care for each other, learn together, act together. This increases our immune system both in our bodies and in our
communities. For example, a village girl in Ayuttaya used to have all sorts of illnesses and symptoms. She was dizzy, had a heavy heart beat, her stomach was all knotted up and more. She is fine now because she entered into the life of her community. She is happy and many of her symptoms have receded. This is the point: that illness was reduced or healed when in the creation of community.

–Prawet Wasi, *Spirituality in the Era of AIDS*

**INTRODUCTION**

Yut stands on the edge of the covered porch area and speaks softly and steadily, her head raised slightly as if to some higher presence. She says she wants to do something useful for Thai society, to give something back. Several women are sitting in the shade of the porch watching intently. Yut has HIV and has known of this since her husband died five years ago. Now as part of a local support group she and other widows from nearby villages come together at her house. They make incense sticks from a mixture of fruit skin, citronella, bark, and eucalyptus leaves to generate a small income, maybe a dollar a day.

She stops speaking in mid-sentence and glances apologetically toward another woman standing off to her left, holding a clipboard. She faces front again and recommences this particularly intimate monologue about being HIV positive. She is speaking directly to a large video camera shouldered by a man on the back of a black pick-up. Again, in a quiet voice, she offers thoughts on how she imagines her life, on how she feels she has learned important lessons about living now that her own life is so threatened, on how these insights have inclined her to do all she can to return something to society. Although gently coached with delivery, it is her own message that she wants to relay so that both she and others can perceive her life as having value. Once this personal testimony is captured, the film crew returns to recording the other women compressing the anti-mosquito incense paste into firm rolls, their palms taking on a deeply pungent sienna hue.

Yut and her friends are being filmed in a northern Thai province in late 1999 as part of a Thai documentary series about those infected with HIV. It has been consigned to deliberately counter the enduring stigma confronted by those with HIV. While Yut is making her speech, her sister, Yupin, is showing me a well-worn photo collection; she stops at several wedding photos of herself and Yut. Flicking rapidly through a handful of albums she points out various people
to me, mostly men. They have all died. She looks up at Yut, who is still facing the camera, and whispers: “I just hope they don’t portray us as ‘pitiful’ like AIDS people are usually shown on TV.” In fact, this is precisely what the show is aiming to counter. Its objective in narrating the stories of many Thai who have gone public (pert peuy) with their HIV status in People Living with HIV/AIDS (PLWHA) groups is to assist in the social normalization of being HIV positive—a condition currently affecting more than two percent of the adult Thai population.

Tanabe (1999) has shown how members of PLWHA groups in Northern Thailand negotiate personal subjectivity and the space of belonging within a community of practice through engaging in activities geared to survival. In this article I also consider forces that underpin identity within HIV/AIDS support groups. My concern, however, is less with the activities that occur within groups per se and more with how the very act of belonging takes specific socially mandated forms that shape membership and social orientation. This article focuses on two aspects of the ways in which belonging is structured within Thai HIV/AIDS care and support groups. First, joining a support group entails forms of self-transformation concomitant with the act of publicly acknowledging one’s HIV status. This transformation is recognized most commonly by an emphasis on visibly correcting a perceived misbalance, which, in turn, functions as an active rebuttal of the stigma widely directed at those with HIV. When considering the nature of belonging, a second characteristic of PLWHA groups becomes immediately apparent. The act of joining groups and “coming out” involves a strategic choice with variant levels of appeal to different categories of people.

This is most obvious in the far greater numbers of women than men who participate. The group Yut belongs to, for instance, comprised 23 women and three men in late 1999. At face value, anyone affected by HIV could join PLWHA groups in Thailand. Clearly, not everyone does, and the reasons for this are many, ranging from personal disinclination and/or practical constraints through to the presence of existing family support or the financial means for alternative help strategies. A further constraint, and one often mentioned to us, is the perceived distinction between male and female aptitudes for belonging in a structured environment of care and responsibility.

Many variables contribute to there being a larger number of women than men in PLWHA groups; however, it is to the emic notion
within groups that gender characteristics play a significant selective function that I wish to draw attention. According to this perspective, gender not only structures vulnerability to HIV infection but it also plays an important part in self-management of HIV and AIDS, particularly in the way it influences disclosure and channels benefits to be derived from belonging to support groups. In local narratives emerging at the turn of the millennium within Thai PLWHA groups, differing levels of male and female participation is offered as one explanation for why men with HIV seem to die sooner than do women with HIV. Clinically accurate or not, this idea has powerful implications. On the one hand, it can be suggested that those joining such groups benefit from the reiterated belief that belonging to them assists in prolonging life. On the other hand, affirming evidence comes at the cost of those who feel less able to become members; in many cases, it comes in the form of the deaths of men.

BACKGROUND

Yut and Yupin are just two of roughly one million Thai who have become infected with HIV since the mid-1980s. Their husbands belong with more than 200,000 who have died. Their group is one of many hundred care/support collectives. Like anywhere else, these three contexts—transmission, morbidity/mortality, and care are basic elements that dictate the impact of AIDS in Thailand. Over the past decade resources have been primarily devoted to prevention activities; however, more recently, medical care and support services have become the priority in terms of overall funding (World Bank 2000:32). Attention was first brought to the rapid spread of HIV in 1988, when the newly instigated sentinel surveillance system shocked the Thai medical establishment and international observers with figures showing rampant levels of heterosexual HIV spread through commercial sex. Throughout the early 1990s the Thai government responded to consistently alarming epidemiological findings with a level of urgency and commitment seldom seen in any country. Through a combination of intensive media campaigns, progressive government policies such as the policed insistence on condom use in all brothels, and constructive collaboration with international agencies and local non-government organizations (NGOs), infection levels began to drop dramatically, beginning in the mid-1990s, in key surveillance groups. Thai army conscripts,
brothel sex workers, pregnant women, and blood donors all showed declining levels of infection throughout the mid-to-late 1990s (Brown 1998). Such drops notwithstanding, in the meantime many thousands of men, women and children were, and continue to become, infected. In 2001, according to the Thai Ministry of Public Health (MOPH), there were roughly 25,000 new infections (sea-aids 2001).

Due to effective campaigning, patronage of prostitution has plummeted throughout Thailand. But in its place there has emerged a more complex and ambiguous arena of negotiated relationships in which casual sex occurs (Lyttleton 2002a). As HIV becomes ever more entrenched in Thai society and individuals distance themselves from well advertised risk practices, precisely how the typologies of vulnerable groups are configured remains a pressing issue for both prevention and care. What is of current concern is that condom use frequently doesn’t accompany sexual interactions that take place outside of institutionalized commercial sex. This raises the threat of continued HIV spread, particularly in light of burgeoning permissiveness and drug use amongst many Thai youth (Supachai, van Griensvan and Kilmarx 2000). Indeed, as one indication of the volatile nature of HIV trends, in 1999 national epidemiological reports showed that, after years of decline, seroprevalence in pregnant women rose again to levels near two percent (World Bank 2000).6

During the explosive outbreak of HIV spread in the late 1980s many more Thai men than women were infected. The logic of this is simple: injecting drug users (IDUs) in Thailand are predominantly male (Weniger et al. 1991:s73), and before campaign initiatives took effect infected female brothel workers had many male clients who eschewed condom use.7 Unfortunately, the logic of what follows is also simple and has been played out in similar fashion across the world. Inexorably, the ratio of women infected has increased. Globally, the percentage of adult women living with HIV/AIDS increased from 41 percent in 1997 to 50 percent of the total HIV infected population in 2002 (UNAIDS 2001, 2002). In sub-Saharan Africa recent UNAIDS estimates show more women than men infected with HIV: 12.2 million and 10.1 million, respectively (Susser and Stein 2000:1042). In 2002 women represented 58 percent of those living with HIV/AIDS in this region (UNAIDS 2002). In Thailand, by the end of 1999 UNAIDS calculated that, of the 740,000 adults living with HIV/AIDS, 305,000, or 41.2 percent, are women (UNAIDS 2000). The World Bank predicted that, in 2000, roughly 50 percent of
new infections in Thailand would be women infected by their husbands or sex partners (World Bank 2000:2).

Studies from many parts of the world highlight the insidious ways that HIV/AIDS affects women. These range from biological vulnerability, to social and cultural norms that disadvantage women’s ability to undertake preventive measures, to aggravated social and psychological morbidity imposed by the presence of HIV and AIDS (Long and Ankrah 1996; Farmer, Connors, and Simmons 1996; Carovano 1991; De Bruyn 1992, Caron 1998). Thailand is no exception to these tenets, although the specifics require elaboration. Mertz, Sushinsky and Schuklent (1996) suggest that women’s sexual vulnerability to HIV, at least in the West, has been overstated and that it has been counterproductive to emphasize the gendered nature of the threat AIDS poses to women. Unfortunately, their argument is not supported by evidence drawn from a wealth of studies conducted in the developing world. It is clear that in Thailand the associated “triple jeopardy” of biological, social, and procreational vulnerabilities adds to women’s anguish.

In the past, women with HIV were thought to die more quickly than men with HIV due largely to psychosocial burden and/or lack of access to treatment resources (Kaplan 1999:188). More recent studies show that women do not progress to AIDS more rapidly than men but, rather, that they do so at a lower viral load than is typical for men (Farzadegan et al 1998:1515). In Thailand many more men than women have died from AIDS: from 1984 to mid-1999 reported AIDS cases number 108,047 men and women 30,603 (World Bank 2000:28). Although the proportional share of women’s deaths is increasing (World Bank 2000:3), there is also a growing perception in many care and support groups that men typically die sooner than women. This conclusion is based, no doubt correctly, on the relative timing of infection: large numbers of women have been infected with HIV from their previously infected husbands. But as AIDS illness becomes more widespread, local explanations also include different ways in which infection is handled and respective options for medical, social, and psychological assistance. Clinical and epidemiological factors of disease progression aside, it is the notion that PLWHA groups offer a very specific form of therapeutic assistance, and that this assistance relies on a management of self (transformation), that concerns me here.

In what follows I focus on the dynamics and make-up of PLWHA groups whose communal solidarity provides the social platform and
moral support for public disclosure of HIV status. As such, these communities have, over time, come to offer a normative framework for being HIV positive in contemporary Thailand. They have emerged as the primary forum through which having HIV is negotiated and normalized in Thai society, a process that is felt by many members to have direct links to an improved and prolonged life. Widespread analyses highlight that “community” is an enduring but pragmatically fluid concept in Thai social and political life, and one that has its roots in the highly symbolic role the notion of “village” plays in what was until recently a predominantly rural culture (see, for example, Kemp 1988). For our purposes it is possible to distinguish PLWHA groups from other more broadly cultural formations, such as kin groups and village-based collectives, through their emergence as identity-based communities formed to mobilize group solidarity and peer group activities to mitigate the effects of HIV. In Thailand PLWHA groups are very clearly the most prominent examples of identity-based collectives to emerge from the presence of HIV and AIDS. Gay collectives and commercial sex worker (CSW) lobby groups are also slowly emerging, but they come as a product of social change well beyond that simply provoked by the presence of HIV. At the time of writing there are no PLWHA groups consisting exclusively of a gay or CSW membership. On the other hand, there are hundreds of groups that have formed specifically to assist a broad membership of those with HIV. And even though Thai PLWHA groups, as identity-based coalitions, might be linked to globalizing forms of belonging spearheaded by international AIDS agencies, it would be wrong to see them as cardboard copy replicas of support groups in the West.

My chief argument is that belonging to an HIV/AIDS support group draws on deeply sociocultural notions of personhood. It relies on the ways in which, on the one hand, self-transformation is required by the presence of illness and, on the other hand, takes specifically mandated forms to reverse the shame and stigma associated with HIV infection. While PLWHA groups share overt similarities with support groups in other countries, I draw on my research in Thailand to show how these conditions differ in how they build on a sense of personal and social realignment to restore balance and to minimize disruption. Such notions are deeply embedded in what we might generalize as Thai culture’s promotion of a sense of self that is strongly tied to the performance of appropriate behavior, what Morris (2000:5) terms “the love of
disciplined surfaces," which is, in turn, linked to one’s social identity. Apart from anything else, in Thailand AIDS is associated with a disruption of order and harmony at both subjective and intersubjective levels. PLWHA groups offer a socially condoned way of publicly reinstating, to whatever extent possible, a subjective sense of “things in their place.” And because it is a public statement, “coming out” as HIV infected abides by enduring assumptions about disease, fate, and causality.

As Tanabe (1999:6) has argued, the notion that PLWHA groups coalesce around practices geared to survival usefully focuses our attention on self-governance and the evolving “ways in which HIV-infected people can acquire and use knowledge to cope with their personal and social disadvantage.” Thus, participation in PLWHA groups is a strategic choice that establishes forms of belonging lodged in specific agreements about group practices thought to be best suited to cope with HIV infection. Activities in the groups I visited ranged from immediate individualized assistance (such as state welfare fund distributions) to collective therapeutic strategies to activities with deliberate community orientation (such as health promotion initiatives and public parades on World AIDS Day). Even though subjective modes of engagement in PLWHA activities are diverse and change over time (7), the performativity of group participation creates distinct and ongoing forms of structured belonging. These structures emerge, and ultimately cannot be separated, from other discursive structures that moderate a sense of belonging within the Thai social order. State and medical institutions strongly affect the experience of having HIV or AIDS. At the same time, more diffuse expectations based on gender and social identity are also part of the complex cultural makeup of PLWHA groups. For while their constituency is large, support groups are not for all: markedly more women than men are drawn to their services, and markedly more married women than single women, suggesting that there is more to belonging to these groups than knowledge of one’s serostatus. How and why this occurs is the question I wish to address. Although women’s entrenched vulnerability to HIV infection is a topic covered in many texts, gender, in its relational sense, has received far less consideration concerning its influence on the dynamics of male and female participation in HIV/AIDS support groups.10

Many thousands of Thai women with HIV are now widows. This creates a need for modes of practical and material support (even as these are reduced or are no longer available within the household)—
a need that directly prompts greater female membership in PLWHA groups. Muecke (2001:35) suggests that strong “socially and morally defined role expectations” invariably ensure that Thai women provide home-based care for their husbands, brothers, sons, and fathers who are ill with AIDS, whereas the reverse seldom happens. In so doing, women caregivers build “positive karma for themselves” (30), while at the same time depleting all personal and household resources. Hence, if or when they themselves become ill with AIDS they have little choice but to turn to community groups for help (Wassana and Suwannarat 2002).

Several studies point to the emphasis on home care and the widespread emergence of community-based PLWHA groups as a product of the government’s inability to provide adequate hospital-based services to the growing number of people with AIDS (Del Casino 2001; Singhanetra-Renard, Chongsatitmun, and Aggleton 2001; Wassana and Suwannarat 2002). Women’s predominant membership in these groups has therefore been linked to class-based variables that dictate women’s (lack of) choice. A majority of PLWHA comes from lower socioeconomic classes (Usa et al. 2001:19), and it is indeed the case that rural PLWHA groups largely serve a poor to lower-middle-class population. There is a widespread perception amongst PLWHA members with whom I spoke that HIV infected individuals who have adequate financial means do not need to join groups as they can seek medical services and/or counseling and emotional support independently. Del Casino (2001:418) notes that, in so far as PLWHA membership is class-based and participants are more likely to be unemployed and/or women, “discrimination still mediates membership.” This discrimination is, however, multifaceted and operates on many levels.

While such class-based underpinnings undoubtedly shape membership demographics in a majority of groups, they cannot be applied as uniform characteristics in every instance. Urban support centers assist people from a wide range of backgrounds. For example, even in its early days of operation, the Wednesday Friend’s Club run by the Thai Red Cross in Bangkok lists its members as coming from a variety of socioeconomic contexts, including shopkeepers, students, construction workers, civil servants, domestic workers, entrepreneurs, and so forth (Werasit and Williams 1994). Though it is certainly common for an individual to return home when sick or anticipating illness, and for many urban workers this means returning to a rural village, social beliefs influence this
decision in complex ways. In a national study, Wassana and Suwannarat report that “many PHAs, both single and married moved back to co-reside with or live next to a parent when ill as lack of income and/or lack of care-giver reduced them to dependency” (2002:22); however, they also note that, in contrast to the north, PLWHAs from northeast Thailand are “likely to delay their return until shortly before death, influenced both by a reluctance to be a burden to their parents, and by the real poverty which faces many northeastern families” (18). In this instance, being poor effectively limits the opportunities that some people with AIDS have to participate for any duration in support groups in their home communities. Contradictory outcomes notwithstanding, economic factors are not the only variable at stake in the disparate levels of membership, and it is important to remember that many join groups for reasons that go beyond material assistance.

A further issue governing disparate membership is the perceived social roles of men and women. It has been argued that women’s predominance in PLWHA groups in the North is a logical extension of the caregiver function (Del Casino 2001; Muecke 2001; Wassana and Suwannarat 2002). From this perspective, the support group becomes an extension of the home, and PLWHA activities are more likely to devised by, and oriented toward, women’s needs. The PLWHAs with whom I spoke confirmed that various group activities, in particular small-scale income-generation initiatives, were only ever taken up by women and had little appeal to men. Del Casino (2001:416) suggests that the particular orientation toward female activities within PLWHA groups has indeed fostered their growth and tailored their financial support yet that they should not be considered as deliberately exclusionary toward men per se. Nevertheless, the perception of a gender-based sensibility within support groups affects membership in diffuse ways and requires an examination that goes beyond overt structural forces such as economic disparities or funding bias. Underlying the proliferation of PLWHA groups in Thailand is a particular sense of belonging in which gender ideals hinder men’s inclination to “come out” as HIV infected. And in so far as disclosure confers assistance at various material and psychological levels, divergent membership along gender lines provides a delayed and subtle counterpoint to entrenched forms of social hierarchy that disadvantage Thai women and their ability to be safe from HIV in the first place. Although I make no attempt to argue that the manner in which social tenets might
constrain Thai men from joining groups is somehow equivalent to the overall imbalances faced by women with respect to AIDS, they nonetheless deserve attention precisely because of the way in which masculinized social identity tends to downplay self-directed scrutiny and reflection within the Thai social order (Lyttleton 2002b).

The formative role that social identity plays in support groups alerts us to further distinctions that determine group makeup. I discuss how normative gender models underscore the ways in which masculinity inhibits collective sharing when health is concerned (but not when forms of male prowess are celebrated in groups, such as in drinking forums, military cliques, and so forth). At the same time, modes of social categorization other than gender (and socioeconomic background) also play decisive selecting functions. For instance, concern about how one’s sexual background will be interpreted is an additional criterion, particularly for women, which either facilitates or discourages joining a PLWHA group. When it comes to belonging within PLWHA groups, single women with HIV are themselves subject to subtle discrimination that separates them from their married counterparts.

Those who join PLWHA groups do so for many reasons. Support groups provide substantial services addressing a range of acute needs, including medical, material, and emotional assistance. They also challenge social discrimination—and the anxiety, fear, guilt, sadness, ignorance, blame, and anger that those with HIV confront—by offering a very specific way of being publicly positive. This entails an opportunity for the PLWHA to reposition his/her life and to refashion a subjective sense of self. Thus, when someone discloses her/his HIV status by joining a support group, s/he also enters a forum that offers the potential to reformulate a sense of “worth” that has been categorically devalued by mainstream associations with HIV in Thailand. For in addition to proving a somewhat effective buffer against high rates of transmission, the initial mass media campaigns made people very afraid of AIDS. Thai prevention programs are hardly unique in this early emphasis, but there is no doubting their effectiveness in creating an enduring sense of stigma associated with HIV infection (cf. Busza 2001). In pockets of Northern Thailand the process of local acceptance is well advanced due to the commonplace presence of HIV and AIDS; but in many places PLWHAs still tell of rejection by family and close kin as well as of more generalized, though no less sharp-edged, prejudice from other sectors. A powerful function of PLWHA groups is
precisely their ability to convert the shame induced by social discrimination into a more positive sense of self-identity.

In October 1999, only days after Yut’s documentary shoot, a photography exhibition in Bangkok opened in a huge shopping plaza. A large black and white portrait of Yut against a backdrop of piled incense sticks appeared as one of 46 photographs of Thai men and women who volunteered to be part of *My Positive Life*. Even more directly than the aforementioned television series, this exhibit sought to change predominant attitudes toward those with HIV. The catalogue made this explicit: “Those affected by the epidemic are generally regarded with fear and perceived as immoral people with no future, waiting to die in a most undignified fashion” (ACCESS 1999:3). Alongside affect-laden photos are comments from each person—comments that challenge this perception. Oom tells us that “Dying is not the problem. Our problem is how we continue living while we are still alive”. In an adjacent photo Odd embraces his wife, both resplendent in wedding attire, and reminds us that contracting HIV “is a mistake that could happen to anyone, and once it has occurred, even though it cannot be corrected, we can still be good people.” These and virtually all the other comments in the exhibition highlight a sense of self that is defined uniquely by the presence of HIV. It profiles a community of those infected. A community that, over the past ten years, has emerged under both duress and inspiration. A community, or, more accurately, a large number of communities, that have come together to address needs of people with HIV and AIDS in Thailand. And, as Yut, Oom, and Odd indicate, how one lives is what is at stake in this process of normalization. Reworking one’s sense of self through the public demonstration of one’s life frequently embodies a desire to contribute something of merit to the social order. It allows for a therapeutic and visible self-transformation. However, as we shall see, for reasons linked to enduring notions of masculinity and femininity the social transformation implicit in becoming a PLWHA arguably demands more of Thai men than it does of Thai women.

Alonzo and Reynolds (1995) propose, following Goffman (1963), that just as HIV and AIDS embody an illness trajectory, so too they entail a stigma trajectory that requires different management strategies at different times. Whether to join a PLWHA group is a choice confronted by many individuals at some point in their experience of HIV infection. PLWHA groups in part perform the social function of allowing those with HIV/AIDS a public and symbolic space, and, in
this respect, a sense of belonging doubles both as a crucial buffer against stigma and as a corrective to induced shame. To achieve this, PLWHA groups rely on both a public presence and a collective enterprise. And, given that this process derives a form of collectivity embedded in social relations at large, it is not surprising that it also shares many prominent social values.

THE EVOLUTION OF PLWHA GROUPS

By early 2002 there were more than 400 care and support groups for PLWHAs in Thailand, most of which are community-based (Thai NGO Coalition for HIV 2002a). By far the majority (close to 250) have mobilized in Northern Thailand, which is the region hardest hit by the epidemic. At the time of writing, in both the Northeast and in Central Thailand (mostly in Bangkok), there were roughly 50 groups; the south of Thailand has fewer groups, reflecting a somewhat slower response to the epidemic (both politically and socially). Some groups meet at local hospitals, others at NGO offices, still others in rented houses or the homes of individual members. In earlier stages, the membership of certain urban PLWHA groups has numbered in the thousands. Nowadays, as local rural groups have proliferated (often as part of decentralized networks), average numbers are much lower, with usually between 20 and 100 participants. Regular meetings are supported by the Thai government and foreign donors through local health authorities and/or NGOs, who provide a core of administrative and varying levels of medical assistance. How often groups meet varies—sometimes weekly, sometimes monthly. The atmosphere and activities in the meetings we attended ranged from informal get-togethers through to formalized training sessions. At times, larger coalitions of several groups meet for planning, coordination, and exchange. Group formation and management has taken place in ways that can be grouped into four broad categories, each with attendant strengths and weaknesses: (1) groups formed by PLWHA themselves (such as the first groups to emerge in the early 1990s); (2 and 3) groups formed by government and groups formed by NGO care-taking organizations (these are the majority of existing groups and vary in capacity and levels of effective empowerment and/or assistance); and (4) groups formed by local community-based organizations (while still numerically few these are considered, ultimately, to
provide the most sustainable form of community assistance) (Araya 1999). Sometimes groups splinter and fold, most commonly when key members die, but overall the number of groups continues to rise.

In 1994 only a handful of support groups existed. Their rapid expansion has made Thailand the focus of international attention and acclaim. The collectives are, of course, in answer to need. But there are many places in the world where these forms of communal solidarity have been less forthcoming. It speaks to a particular combination of social and religious sensibility, community and government action, and, at times, foreign donor promotion. A crucial element has been the courage shown by many of those with HIV who have taken on seminal leadership roles in respective groups to offer the first collective face of living with AIDS in Thailand.

The characteristics of PLWHA group formation vary somewhat in the different regions of Thailand. It is suggested by some group leaders that the different tenor of NGO organizations in the Northeast (long characterized by an active, at times militant, NGO sector working for equity in rural development) have given support groups a more regimented mood, at times forbidding drinking or smoking amongst members. The levels of public acceptance in the Northeast have not yet reached those seen in the North, and, in this sense, there is still a perceived reluctance for individuals to “come out” in their home communities (cf. Wassana and Suwanarat 2002), which, in turn, has led to there being somewhat less coordination and concentration of groups in the former than in the latter. In Bangkok, the sheer size of the urban environment colors the sense of community orientation and personal intimacy that most rural-based groups engender. Some men and women from neighboring provinces join groups in Bangkok rather than in their home communities for the greater anonymity it confers. Group members also suggested that Bangkok groups are more politically oriented and activist than are others due to their proximity to state bodies.

Nevertheless, there are general trends in the evolution of PLWHA groups throughout Thailand that reveal the normative frameworks shaping membership. Although the first support group, the Wednesday Friends Club, was started in Bangkok in 1990 as an offshoot of the Thai Red Cross Anonymous Clinic, it wasn’t until several years later that community groups became widespread. Reflected in the numbers of groups, initially this expansion received the most social and financial encouragement in the upper provinces of Northern Thailand. A recent UNAIDS report prepared by local
researchers and AIDS workers historicizes northern Thai PLWHA groups by plotting them within four phases (Usa et al. 2000). Its typology provides useful signposts of the sociocultural forces influencing group formation. First, the Suppression Phase (prior to 1993) is characterized by an overwhelming sense of stigma and social shame directed at those with HIV. This was so strong that it made it impossible to publicly acknowledge being infected, and people “found themselves without a moral and social space to defend themselves” (2). Throughout the brief history of support groups, certain events have become key, almost mythic, milestones in its retelling. The first takes place in 1993 when a traditional healer in Chiang Mai advertised that he had an herbal remedy for AIDS. Mor Wichai quickly gained widespread notoriety as a “divine” healer (mor tewada), and for a period more than a thousand people came to rely on him for herbal treatments (Seri 1996:1). His services were short-lived and he was arrested in February 1994 for peddling what the authorities claimed were sham cures.\textsuperscript{14} Galvanized by what was perceived as one more indication of how little respect they commanded, PLWHAs mobilized to challenge this indictment. Although, the “doctor” himself never gained his prior stature, the outcome was the formation of the New Life Friends Centre, which was initiated by a core of the PLWHAs who had established a small network when they met at his house (CDC 1997:9). These people gained a grant and rented a house where they could meet to exchange information on health care and to distribute medicines. In a short period of time membership grew to over 2,000, with hundreds joining each week.

The profile gained by the New Life Friends Centre, which sent a delegation to meet the prime minister over the herbal treatment “scandal” (Seri 1996:2), ushered in the Strengthening Phase (1994–96), when support groups in the North expanded after the New Life Friends Centre split its membership into a number of affiliated rural-based groups (Shah 1996). Activities within these 35 groups were primarily geared to income generation, gaining access to treatments, and sharing moral support and knowledge about medical and self-care techniques—activities that remain the mainstay of most PLWHA groups today. As one example, the Community Care Network (begun in 1997 just outside Chiang Mai and comprising a number of PLWHA groups in neighboring districts) orchestrates the following services: home visits to those with HIV or AIDS, including counseling and material assistance; emergency funds for the
seriously ill; income generation, including fund raising and support for local initiatives; regular meetings for medical and social exchange as well as a referral service; child care for local children; local community outreach, including prevention and awareness activities; and coordination with NGO and government bodies. These activities, often more informal than they sound, are typical of many groups. It can be seen that group members come together both for self-directed remedial treatment (such as meditation and herbal medicine) and for activities oriented to the wider community. Through this dual orientation, this phase marked the establishment of a public space from which self-admission of HIV infection could lead “to a ‘recovered’ sense of self worth and self-reliance” (Usa et al. 2000:4).

These initial coalitions were given seeding support from government and non-government “caretaker” (phi-liang) organizations that provided medical, financial, administrative, and, at times, spiritual assistance. The 3rd Asia Pacific Conference on AIDS held in Chiang Mai in late 1995 was the second seminal event from which new-found empowerment radiated in diverse ways. Here for the first time many Asian and Pacific men and women with HIV came forward to present a public face and impassioned voice to a broader social world—a world that, to date, had been more concerned with avoiding any contact with HIV or its embodiment. A highly publicized draft policy document designed to protect the basic civil and human rights of those with HIV was prepared by a coalition of HIV-infected activists. People with HIV from throughout the region described the occasion as providing a grounding for an expanded sense of belonging. The conference highly profiled the sensation that having HIV, rather than being simply a brutal indictment, could also evoke a profound sense of connectedness. A complex dimension crystallized when Phimjai, the well known leader of a local community group, publicly uttered a simple phrase that took on the power of a mantra for those with HIV: “Thank you AIDS.”

The sense of collective empowerment led to the establishment of a network of PLWHA groups in 1996, which, in turn, fostered an explosion of new groups in many rural districts throughout the North (and other regions). In this Branching Out Phase (1996–98) the number of groups in the northern provinces grew from 35 to 195. This expansion reflected most of all the increased ability of PLWHA groups to garner financial support and encouragement from state and non-government bodies. It also established the idea that support
groups should be integrated within local communities, thereby replacing the ethos of exclusion with the idea that the public and social space of AIDS rightly belongs at home. The ideal of community integration has been signaled as the next natural stage of the evolution, one that is still tentatively taking shape. This has been labeled the Reconciliation Phase (1999–present), and it imagines the removal of the need for orchestrated groups altogether. It promotes the idea that there need be no special recognition for those with HIV: they should be able to take their place within their home communities (or whatever communities in which they wish to take part) without the need for being separately identified with HIV/AIDS. Those spearheading this conceptual shift clearly appreciate that it will appeal more to some than to others. Many PLWHAs feel strongly that, while complete acceptance may be an optimal goal, not only does it remain a long way off but it also may be seen as counterproductive in that support groups generate funds precisely through their collective mobilization.

BEING PUBLIC AND THE TRANSFORMATION OF SELF

The rapid expansion of PLWHA groups in Thailand highlights the fact that, in earlier stages of the epidemic, those with HIV had neither the sanctioned opportunity nor the moral support to disclose their infection. However, the space that has subsequently been created has its own moral and social parameters, and these must now be negotiated. HIV/AIDS, like any other illness, is an embodied experience carved by multiple forces. The dialogic nature of having HIV creates an ongoing process of coming to terms with illness, which allows the potential transformation of one’s attitudes and physical state (Tanabe 1998). This transformation becomes visible in the act of public disclosure when joining a support group. The names of many groups, such as Yut’s group, “the New Dawn,” or “the New Life Friends,” reflect this sense of a new beginning. Many speak of how joining groups was like being reborn (gert mai). A coordinator of PLWHA groups described the hesitation felt by those considering this rebirth.

Having AIDS is like being in a burning house; people run to the top of the house trying to escape the fire. Down below people are calling them to jump—but those in the house are not sure whether they will be caught safely. So some stay in the house—and die quickly. Some jump
their status] and are better for it; others are maybe not caught safely. Those that stay in the house are unsure whether to go public with their HIV status, they don’t know whether this will help them in any way.

Most PLWHAs from support groups believe in the therapeutic benefits of belonging. Not only does membership provide improved access to resources and encourage a more systematic appraisal of health strategies but it also offers members a form of sharing that, precisely because HIV has come to define so much of their current identity, is impossible to find elsewhere. One PLWHA described the commonality as akin to kin groups of “the same bloodline” (sai lu’at diawgan). With zealous enthusiasm, some members do their best to persuade others who might be HIV infected to join. Contact is made in numerous informal ways, often beginning with home visits; but the underlying sentiment appears relatively uniform. We frequently heard one descriptive phrase that evoked the desirable transformation implicit in coming out: “Before I was in the darkness, now I am in the light.” Somkhiat explained that a primary reason for his recently joining a group just outside Chiang Mai was so that he could help others to “see the light” by dragging them from the darkness of solitary HIV infection (du’ng phu thit chue jak mu’t thu’ng sawang). This metaphor of moving from darkness to light is a common trope for many sorts of psychic transformation (and the staple of numerous types of support group in many countries). Here we see it emphasized around forms of sharing that help clarify and make manageable the vast complex of emotions, in particular the anguish, both personally and socially induced, invoked by AIDS. Thus it denotes a reorientation to the larger social and spiritual world.

Tanabe (1999:17) suggests that the groups assist PLWHAs in “self-fashioning their existence as an ethical subject.” He sees this orientation as inner directed, enacted through techniques (such as holistic care) that promote the harmonious relationship between mind and body. This is an ethos that is suffused by a Buddhist conception of balance within one’s life. However, as we have seen in the array of specific activities, the construction of an ethical subject through belonging to a PLWHA group also involves an outward orientation which is implicit in being public. It is a perspective geared to being in harmony with the larger community and, as such, also takes on instrumental and moral connotations that must be negotiated within the governmentality of larger state and social structures. Gatae,
echoing many, told us she wanted to get others to also go public so that they could collectively help society, so that their lives would not be in vain (mai tai plaw), so that they could ensure that their HIV infection had some positive meaning for those to follow.

The decision to reveal one’s status to others depends on many factors and, ultimately, involves a strategic choice—one that will be determined by the perceived benefits of disclosure outweighing the disadvantages of a loss of privacy. Most commonly, amongst those we interviewed, it occurs in stages, beginning with partners and/or family. For some the rights of PLWHAs is the overriding incentive, and it is one that is becoming more common as, following political changes, civil rights in general have recently gained much public support throughout Thailand. For a majority, access to treatments, knowledge sharing, and emotional intimacy appear to be key factors. Inevitably, the range of motivations involved in joining is inflected by how support groups reproduce certain social values.

Numerous cultural analyses routinely suggest that the Thai, most of whom are Buddhist, place great stock in maintaining the semblance of harmony in the social order, in preserving an unruffled surface (Morris 2000:48). Adherence to this ideal tells much about one’s moral endeavour and the attainment of a “balanced life” (samajivita), following the Buddhist doctrine of the middle path in face of all phenomena being in a constant state of flux (Siddhi 1995). Mulder (1990:106) offers a populist distillation of this notion: “The orderly fulfillment of one’s place in a predominantly hierarchical society defines the person as ‘good.’” From any number of perspective’s, AIDS disrupts a sense of prevailing order, from the immune system to gender’s structuring of sexual access to what is described as an overwhelming burden on the economy. Over the years popular understandings of AIDS in Thailand have elaborated deeply embedded cultural narratives of contagion and danger, desire and safety (Lyttleton 2000). For many who are affected by HIV and AIDS, courage and compassion have rebuilt composure and stability. At other times, as the exhibition Positive Lives attempted to show (and, in showing, to assuage), AIDS has given a strident vocabulary to people who wish to condemn those seen as personifying disruption.

The concept of appropriate behavior—which Van Esterik (2001:36) glosses as kalatesa, which technically means proper, suitable, or balanced but, idiomatically, means “social cosmetic”—has a strongly performative role in structuring the expectations and
experience of being affected by HIV. Social relations throughout Thailand hinge on preserving appropriate interactions and, at the same time, maintaining an awareness of surfaces allows social exchanges to take place without an elaborated exegesis or a public examination of more deeply embedded emotional attributes. The rapid growth of support groups must be understood in this light. These groups offer a way of being public with HIV infection that adheres to a socially condoned way of expressing this condition and its affective entailments. Typically, public disclosure involves a reorientation wherein one’s life takes on increased value through changed practice—value that is gained by actions that are oriented not only toward self-preservation but also toward community. Bechtel and Apakupakul (1999:471) use an associated concept to make a similar point: “While believing that suffering is an integral part of life, Thai’s [sic] also believe that krengjai, or considerations of social rules and protocol, is essential to family life and harmony. Krengjai becomes a model where social roles are understood, interpersonal conflicts are prevented, and the community and spiritual harmony become the accepted way of life.” According to these authors, HIV/AIDS and its ensuing social isolation creates “chaos” from an otherwise “harmonious and hierarchical spiritual framework,” and their HIV-infected informants in Southern Thailand consistently attempt to re-establish krengjai through rebuilding family and community networks and fulfilling some social purpose (472). Whether we regard the public face of HIV infection in the PLWHA groups as emerging from emic concepts of kalatesa, krengjai, or samajavita (or some combination thereof), we unmistakably detect the underlying cultural logic in the visible emphasis on rebuilding harmony as an ideal and normative social response to the tremendous damage HIV/AIDS has wrought in Thailand (cf. Thai Development Newsletter 1996).16

Yut’s quiet comments to the TV camera thus become a chorus: irrespective of how selfless they have been in the past, many PLWHAs wish now to publicly concentrate on doing things that are demonstrably “good for society.” Kinkaew echo’s the refrain: “When I learned I was positive, others looked on me as if my life had no worth. Now I have regained a sense of self-worth [mi khu’n kha] from doing things for others [tham peua khon un].” Almost wherever one talks with members of PLWHA groups, they repeat this message and cite AIDS as a crucially poignant learning experience.17 Thus, in his personal record of being positive, Anan tells us: “I am deeply
indebted to everybody who has helped me get my life back and I am determined to live my life for the benefit of society” (Seri 1996:5). These and many of the preceding descriptions are personal sentiments and, in an experiential sense, may be typical of those confronting a radically redefined life expectancy in other cultural settings as well, in particular facing a condition that has been as universally stigmatized as has AIDS. But such constant repetition must also be interpreted within the cultural context from which these ideas emerge.

Taussig’s (1980) suggestion that an organizing realm of moral concerns underpins the formulation of any disease theory takes on particular resonance here. The “why me” and “why now” questions are inevitably provoked for anyone with HIV and, if not completely answered, are at least supported by the Buddhist belief in karma as an explanation of moral causality. Importantly, this philosophy suggests that the implications of signal events can be adjusted or, from some perspectives, atoned for. According to Siddhi (1995:133), doctrinal concepts of “impartiality” rely on this notion of karma and lead Buddhists to consider why they do what they do and endure what they endure: “Thus, one reflects that everyone’s action determines his or her own fate and destiny, and whatever befalls him or her, they have brought it upon themselves, and that only they themselves can alter their fate or destiny.” Culturally condoned forms of being publicly HIV positive and certain emotional presentations of its embodiment, therefore, fit closely the social expectation of repairing what is perceived as a disrupted social condition. They assist in maintaining or restoring the unruffled surface; they help to sidestep the shame associated with an out-of-order condition. And, based on a cultural logic of redemption, joining a PLWHA group offers a prime opportunity for re-establishing the “orderly fulfillment of place.”

Further examples of this collective orientation can be seen in a UNICEF-sponsored video entitled With Hope and Help (Living Films:1997), which featured Thai PLWHAs who uniformly stressed themes of living in harmony with HIV in one’s body and the benefits of publicly coming to terms with being positive in a way that society appreciates (primarily by [re]proving one’s worth). Ede tells us something of her life with HIV: “I help with rural development work so that villagers can see that people with HIV can still benefit their communities and they can still work and they can still help others. That’s made a big difference in the way villagers think of people
with HIV.” Daeng, from Clear Sky Foundation, expresses a similar sentiment:

Lots of people say that everything about AIDS is terrible. They say that it brings shame to the family and destroys society. But those of us who are infected are rising up and accepting the fact that we have HIV. We are leading lives that are positive examples to all those people who still don’t understand.

Another suggests to the audience that pressure should not be put on people to disclose but “you [the person who goes public] should be ready so that you can really help people when you do open up.”

Hence, key narratives of social activism and social welfare for the benefit of Thai society have emerged as a major trope in the discourse of HIV/AIDS social support groups. Some HIV positive people see their roles as being spokespersons for encouraging people take the presence of HIV more seriously; others simply state that “if we do good in this world then the world will be good to us” (Living Films:1997). Therefore, one emergent role for PLWHAs in community groups involves stepping forward as advocates of the changes needed to increase acceptance, to allow room for human dignity and to sustain the continued need for care both in the sense of safe practice and in the sense of social compassion. And, in so far as they take the form of emotional appeals oriented to local community, such practices pose an interesting contrast with collective solidarity movements like those that emerged around the AIDS issue in gay communities in the West. As Ariss (1997) and others have documented, in many Western contexts there was a period in the social history of AIDS when being HIV positive channeled an emotional experience into the strategic deployment of anger to actively and directly challenge government policy (though clearly there have also been many organizations that have been more directly oriented towards caring and lessening the social impact of AIDS). While political lobbying does (increasingly) take place in Thailand, being publicly HIV infected has so far been more concerned with creating a particular social and moral space—a space that does not overtly disrupt but, rather, meshes smoothly within the Thai social fabric—to mitigate the shame that has so commonly clung to PLWHAs over the years.

Despite a certain degree of common, perhaps global, language deriving from shared experience at donor-funded conferences and training sessions (organized by international AIDS organizations), these sentiments emerge from a wellspring that runs deeper than
orchestrated group solidarity. It speaks to a sense of belonging and unburdening in face of the terrifying solitude of keeping HIV infection a secret. One person with whom we spoke offered a particularly evocative metaphor: “Those that don’t disclose are like frogs in a jar.” In other words, their worldview is limited: they are locked in a situation over which they have no control. Leaving the jar is like jumping from the burning building—an escape into a better life.

It is widely accepted in clinical circles (in the West) that disclosure and positive thinking has concrete and largely beneficial implications for one’s well-being (Friedland, Renwick, and McColl 1996; Wilkinson and Kitzinger 2000; Taylor et al. 1992). Even though few Thai PLWHAs are convinced that they have sidestepped the fatal forecast of AIDS,20 one of the most therapeutic aspects of joining groups is the perceived correlation with a longer life. While much of the popular sentiment implicit in joining a group is linked to the extended network of “real friends” who share the experience of living with HIV,21 there is a growing narrative within PLWHA groups that shared activities and, particularly, helping others prolongs one’s own life. This coping sentiment was particularly honed with women who wished to live as long as possible to take care of their children and to be able to transfer whatever merit (bun) that they could (increasingly) derive in this life onto the lives of their offspring. While not restricted to rural areas, this was a far more common attitude there, where groups were based in local communities, than in urban centers or hospitals. Pointedly, many Thai PLWHAs felt that the ability to be able to prolong one’s life through the management of self was a benefit more readily available to women than to men. This rationale stems from a sense of belonging within a local community that hinges on how one’s life is assessed, for inevitably and across a wide range of contexts AIDS incurs forms of adjudication based on normative understandings. This is an issue of everyday behavior not just in the present but also in the past. And, in keeping with prominent HIV discourses, when HIV infection is involved one’s gender has strong implications for how one’s history is judged.

GENDERED BELONGING

In some large groups in urban centers there is seemingly no obvious gender imbalance. In fact, in Bangkok’s Candlelight Club, some
male PLWHAs suggested that, due to reticence in front of many male members and the lack of free time to travel the distances required, women were less likely to “come and hang out.” But overall many more women than men come out as PLWHAs, particularly those women who return to their home communities, which, throughout Thailand, remain predominantly rural. As mentioned, in most rural support groups in the North and Northeast there are markedly more women members than men: one study conducted in 1997 showed twice as many women than men belonging to a sample of 29 groups in Northern Thailand (Del Casino 2001:415). Women made up between two-thirds and three-quarters of the members in most groups we visited in the North and Northeast. This indicates that, more often than not, men and women take different approaches to the decision to go public. By the same token, it suggests that opportunities to benefit from collective solidarity are tempered by gendered concerns.

The first and most obvious explanation for this is that more men with AIDS than women with AIDS have already died. This is certainly the case, by as much as 3:1.22 Indeed, one of the first self-help groups to mobilize in the North was the Doi Saket Group for Widows (Glum mae mai Doi Saket). It is undoubtedly true that, when men become ill sooner than their spouses, they are often taken care of within the household in ways not subsequently available to their widows (Muecke 2001). The death of a husband creates special needs for the remaining spouse and her children, and these are directly addressed within the PLWHA groups. However, in and of itself, mortality is not an all-encompassing explanation. Not counting those who have died or are ill with AIDS-related illness, more than 700,000 Thai men and women are believed to be infected. While a majority are perhaps still unaware of their infection,23 there are currently about 50,000 new diagnoses of HIV infection per year in Thailand (Marcan-Marker 2002), and there remain social factors that inhibit many of these men from joining support groups. It can also be argued that men tend to be away from their home communities more than women. Again, this is a partial and unsatisfactory reason: in many contexts both men and women either commute to, or migrate for, work. In addition, therefore, we need to consider how a sense of belonging is gendered. Why are more women than men inclined to join PLWHA groups? Beyond purely economic and demographic rationales, one important answer lies in the way Thai society controls the cultural meanings of being publicly positive.
Shame prevents or inhibits disclosure, and it affects both men and women. A study that attempted to quantify psychological stressors affecting HIV-infected women in Bangkok showed high levels of shame and reluctance to disclose: more than 50 percent had not told anyone beyond their partners of their infection (Bennetts et al. 1999:746). So while it is impossible, in any quantifiable sense, to say women feel less (or more) shame than men, shame influences decisions in different ways. There was a general consensus amongst the PLWHA with whom we spoke that men open up and adjust to having HIV more slowly than do women. One prominent counselor and group leader, who is herself HIV infected and not only helps those within her rural community but also spends time in Bangkok assisting wealthier individuals who make private appointments with her, describes the differences she notices between men and women:

Men accept being positive with more difficulty than women and they think of suicide much more frequently. Generally men will decide to come and talk more quickly than women do but they have greater difficulty coming to terms with HIV infection. Women take longer to come and talk but once they do, they adjust themselves much more quickly. Men are far more rigid in their responses—unable to accommodate the changes implied by having HIV—they are only creative when it comes to thinking of ways to commit suicide.

This example is typical of general explanations from many PLWHAs for the gender variance within group membership. In other words, in many support groups certain attributes of masculinity are used to explain why fewer men than women decide to join support groups. It is not just that men receive more care from women members of their individual households that forecloses their need to join groups (although obviously this lessens the need for immediate practical assistance). Both men and women who do belong to groups suggested that gender status also inhibited disclosure: men are supposed to be seen as the leaders (phu nam) who don’t need help from anyone, and showing the need for ongoing emotional support is to publicly demonstrate an unmanly form of weakness (on-ae). Likewise they have no patience for the female-oriented activities that occur within groups (such as income-generation schemes involving sewing or manufacturing stuffed toys) (Safman 1999), which they perceive as trivial and unmanly.

And yet, as many women were quick to point out, such demonstrable masculine “strength” simply highlights an underlying
weakness—the inability to deal with overt signs of AIDS and, most significantly, the inability to ask for help. Many PLWHAs, both men and women, feel strongly that belonging to a support group reduces psychological morbidity and prolongs one’s life (a belief that, in itself, is in all likelihood strongly beneficial). This is the key reason given for wanting to persuade others to join. Thus, gender normative men are perceived to be at a disadvantage: first because they have a lesser innate proclivity for receiving and giving emotional succor than do women and second because gender barriers hinder their chance to join PLWHA groups (where they could develop such abilities). In short, many infected men do not readily gain access to forms of assistance that might prolong living with HIV. In the groups I visited, men that do join typically do so only when they become ill. Thus, unless treatments are successful, they tend to be short-term members, which, in turn, limits whatever benefits might accrue from membership. While these are broad generalizations, and while many men do not fit such gender stereotypes and do not find these constraints prohibitive, the consensus from most PLWHAs was that many (primarily heterosexual) men are excluded from belonging by their “natures” rather than by anything else.

Long-term systematic gender differentiation inevitably embodies social values. As Bourdieu (2001:61) notes, “Collective expectations, positive and negative, through the subjective expectations that they impose, tend to inscribe themselves in bodies in the form of permanent dispositions.” It is not surprising, therefore, that perceived gender distinctions are used to explain elements of the embodied constellation of psycho-social conditions experienced by those with HIV. Hence, in popular narratives of the efficacy of many PLWHA groups, men are frequently thought to die more quickly than women, notions that confirm, in circular fashion, the therapeutic value of joining groups in the first place. Women members of groups (and some men) suggested that men give up more readily (yorm phae ngaikwa) because they have less well suited psychological tools upon which to fall back. Others, such as Noy in Khon Kaen, noted that men “don’t fight” (jai mai su) what is perceived as an irreversible death sentence. Such descriptions highlight that women, in contrast to men, are thought to have both the skills and the inclination to better come to terms with HIV because of their gendered and socialized responsibility to family and children. Women PLWHA members described their focus on helping others as crucial “medicine”; they note that men who do not join or who come only in
the latter stages of their lives have little access to this means of assistance.

Group members apply the generalized inflexibility that is considered to promote early male death in two overlapping ways. It emerges first in a sense of psychological denial, wherein men are deemed unable to accommodate their diagnosis, and second in terms of a direct confrontation with AIDS, wherein men demonstrate disdain for “taking care” of their health. Women, for their part, felt that they directly improve their lifestyle and live in greater “harmony” with the virus because of their innate feminine qualities (although some consider that physiology also plays its part: there is a widespread belief that menstruation prolongs life). A study of mortality rates, for example, notes: “It is likely that AIDS widows can live longer than their husbands as women with AIDS are more likely to take good care of themselves” (Wassana 1998:7). Gender characteristics carry further distinctions. Generally, single men are regarded as the most likely to simply embrace a life of prolonged hedonism (especially drinking) and to “just let life go.” Married men seemingly have more to account for, and here psychological dilemmas are paramount. A number of widows explained that their husbands had died more quickly because they just gave up, being burdened by guilt and despair—guilt at having introduced HIV into the family and despair at having no way to rectify this.

Even though these stereotypes are not actively created by PLWHA groups who might, in many instances, attempt to overcome them, the rapid expansion of support groups has profiled and perpetuated their presence. Moreover, forms of social understanding discursively shape the experiences of those with HIV and AIDS both within and without this community of practice. Underlying all these descriptions is the notion that public acceptance—from family through to one’s local community through to society in general—is essential to a life less at odds with AIDS. While acceptance and, thereby, redemptive transformation is, at face value, on offer to all within the PLWHA groups, certain individuals are offered more help jumping from the “burning building” than are others. Acceptance and the opportunities for transformative management of self are based, in part, on a sense of personal history, and there remains a subtle but powerful sentiment that how one is accepted will depend on how one carries oneself. And how one carries oneself will depend on one’s starting position in a hierarchy of prejudice associated with AIDS. A common goal assumed by
PLWHA groups is to demonstrate to society that people with AIDS should not be devalued: this is part of the transformation that joining entails, a revitalized sense of worth. At the individual level the same attitude applies. This involves a consideration of both past and present, for to re-establish worth, a starting point is necessary. As Uey, in a group near Chiang Mai, explains:

How people accept you depends on your previous behaviour—the sort that has not had good relations with the community, the type that likes to be short with others or deride them will be seen to have deserved what they get \[som nom na\]; but if they have taken care of others, helped around the village, then they will be more readily accepted.

And Bualoy describes the reaction from her local community in Northeast Thailand: “Some folk were understanding; others were scared of me. Those who had envied me felt I deserved it.” Other studies confirm this pattern: "Community assistance to PHAs exhibits considerable gaps however. The community is likely to provide assistance to those considered to be responsible members of the society or those who have previously contributed to the community” (Wassana and Suwannarat 2002:29).

In addition to personal masculine traits that hinder disclosure in a group setting, for a number of men, in one important regard, this consideration of the past offers a further impediment: because HIV infection has been targeted as the individualized product of a dereliction of duty toward oneself and one’s family, joining groups is tantamount to admitting personal “negligence.” Following years of media campaigning, a man acknowledging HIV status is most commonly identified with commercial sex and an accompanying diffuse sense of shame born of being associated with a source of contagion.26 If the men are unable to breach this barrier, if they are unable to embark on the steep incline of self-transformation, then they are left to dwell \(khit mak\) on such dilemmas alone. One woman described men who don’t join groups as more likely than women to become enormously anxious over symptoms and any physical irregularity to the point that such obsessive concern itself leads to an early death.

Women, on the other hand, are perceived as innately caring (which makes mutual emotional support “second nature” to them) and, at the same time, likely to have incurred infection from their husbands. In part, therefore, the larger number of women in PLWHA groups is a product of timing of detection. Given a wide-
spread disinclination for voluntary testing, quite often men don’t learn about their infection until they get begin to get ill. This, in turn, rolls the dice for married women who, as soon as their husbands show signs of sickness, are immediately suspected of having HIV. At these times coming out is forced on women in ways different from those experienced by men. Alternatively, a large number of women learn of their infection when they become pregnant, and here, in many cases, awareness is forced on both husband and wife. But while more wives seek assistance in community-based PLWHA groups than do husbands, the sense of belonging experienced by the former does not necessarily extend to single women.

Once again, acceptance is conditioned by one’s personal history and the availability of moral frameworks that permit HIV status to be anchored within a social identity. On the one hand, women who have become aware of HIV infection through marriage are readily encouraged to join PLWHA groups. Typically, they are expected to assume the caring role both for themselves and their ill husband (and children) and are offered ready moral and emotional support in these ventures. On the other hand, the same social tenets that demarcate subtle blame disadvantage single women, who seldom belong to community-based PLWHA groups. When I queried groups about this, the answer was virtually unanimous: single women would not feel comfortable admitting they are positive in the absence of an “acceptable” vector of transmission (i.e., a husband). Subtle barriers make joining certain PLWHA groups difficult because it requires openly admitting to becoming infected outside of marriage (and this is most commonly associated with commercial sex). Just as some men join groups away from their home communities for the anonymity it confers, so single women tend to join larger urban groups. While, overall, infected married women might outnumber single women, commercial sex and rising levels of youth promiscuity imply that a number of unmarried women are positive. At present they seldom join local community-based PLWHA groups, and if they live in rural areas their marginalization is increased.

CONCLUSION

Each year tens of thousands of Thai men and women learn they are HIV infected; over a hundred die each day. Just as sexuality and gender shape vulnerability to HIV infection, so too they shape
complex sociocultural dynamics within HIV support groups. For example, issues of marriage within PLWHA groups and how to consider possible pregnancy are treated in public forums as highly contentious and are further complicated through the media depiction of HIV infection as a form of immediate desexualization. A very powerful function of PLWHA groups is that they allow their members to challenge the dominant trope of becoming HIV infected and/or ill with AIDS as a social trauma. If we interpret the strategic public countenance of PLWHA groups as engaged in what Das and Kleinman (2001:4) term a “politics of recognition,” then we must also be clear as to how “this form of politics is itself anchored to the material, moral and social aspects of everyday life in marginalized communities.” Sheper-Hughes (1994:992) has argued that consistent attention to an individualized human rights ethos within AIDS prevention programming can detract from a broader perspective that considers the insidious damage AIDS wreaks upon the social body and all those who belong therein: “I look to a more collectivist—dare I say ‘womanly’—social ethic of care and responsibility.” Her suggestion of a feminized, “more inclusive,” sensibility is apposite.

Looking collectively rather than individually, we see that patterns in belonging and inclusion do indeed emerge and that they variably govern opportunities for challenging the shame associated with HIV. Subtle forces shape belonging within PLWHA groups. These groups offer different levels of appeal to different categories of people, who make strategic choices about the potential benefits they offer not the least of which is a process of normalization involving acts of moral re-affirmation that directly rebut stigma. At one level belonging is an individual decision. For instance, middle- or upper-class men and women with financial security and access to high quality medical assistance, coupled with a concern for status, are likely to remain outside the umbrella of PLWHA groups communal services (although there is talk of providing Internet-based services for people in this category). At another level, social forces strongly direct, or discourage, decisions to join. Drug users and single women find it difficult to gain access to support groups outside the large urban centers, and even there many find disclosure prohibitive. Men in general form a constituency for whom belonging is obstructed.

Even as some men join PLWHA groups readily (and often assume major leadership roles), for many more cultural notions of an
essentialized maleness preclude participation. In a social order that privileges masculinity in numerous ways, it is this very privilege that denies men various forms of exposure and sharing. I have argued elsewhere (Lyttleton 2002b) that Thai women are subject to lifelong forms of scrutiny in ways that men are not. Public disclosure through entering a PLWHA group entails a form of examination, exposure, and transformation that is unfamiliar to many men. Yet in a somewhat ironic twist, it is precisely this “opening up” that is deemed one of the most therapeutic aspects of joining. Thai women’s sensibility, in a phenomenological sense, is stereotyped as those who must “think a lot” (khit mak). This feminized characteristic is imbued with the unremitting responsibility for the everyday details of life that Thai women are expected to assume and that Thai men (as practicing Buddhists) are expected to relinquish. “Thinking a lot” is believed to make women vulnerable to all sorts of illness (Muecke 1994). Now, in a telling departure from typical use, I often heard this phrase employed to describe men who are HIV infected. Those unable to come to terms with being positive, who feel unable to seek emotional assistance in PLWHA groups, are destined, it is said, to dwell on things alone (khit mak) and, thereby, to hasten their demise.

Hence, we can reiterate that the swathes that AIDS cuts through any society are frequently deep and that at times the damage is clearly defined. Poor women throughout the world have, in particular, been distressingly vulnerable to its destruction and pain. However, at other times the impact is not so cleanly defined, and we find that imbalances have moments of both counterpoint and reversal. For years, Thai women were targeted as “the dangerous other” through the bodies of the many who have been impelled into commercial sex by a social order that privileges the commodification of female sexuality. This stigma was a consequence of a social hierarchy that treated women as “natural” scapegoats. Nowadays, men’s involvement in commercial sex also carries negative conceptual consequences. In addition to the physical implications of HIV infection, previous behavior has become an obstacle for those desiring disclosure. For a majority of men this perhaps remains a relatively minor hindrance as commercial sex received little social sanction prior to AIDS; however, these days a newly imbricated sense of responsibility for incurring infection combines with more entrenched constructions of masculinity to incur more concrete effects. Although Thai women clearly bear the brunt
of aggravated vulnerability and demands for care, Thai men are also subject to gendered dilemmas. They are beholden to forms of sociality that make them less familiar with moral empathizing and the reflexivity this requires, which, in turn, inhibits their joining PLWHA groups. If these dynamics of PLWHA group participation are sustained, and if they reflect expanding modes of belonging for HIV positive people in Thailand, then the ways that local narratives, which shape their formation, are anchored in moral and emotional terms has tremendous consequences. Drug treatment aside, in so far as disclosure is a benefit, men’s lives are possibly shortened for the same reasons that women’s lives are possibly extended.

The discursive strategies that shape support groups are embedded within local moral economies and frameworks of meaning, and this results in effects that are not always intended or desired. And this occurs to the extent that PLWHA groups, and their attendant technologies of self, engender illness differentially, with dramatically embodied consequences. While not the only variable, gender plays a significant role in this process and warrants attention in deriving a more encompassing form of care so that the ethos of living in “harmony” with AIDS, to whatever extent possible, may become a widely shared social goal. Thus, the onus is on donors, facilitators, and caregivers within, or affiliated with, these groups to appreciate the impact of gender (particularly masculinity) on the functioning of these groups. Women’s psychological and physical needs must be adequately covered within these groups. At the same time, men’s and single women’s (and other social groupings’) avoidance of support collectives must be addressed before such service provisions even become possible for them.

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NOTES

1. The ethnographic fieldwork that provides the basis for this article was conducted for two months in late 1999 as part of my long-term research into the impact of HIV and AIDS in Thailand. Together with a research assistant I conducted open-ended interviews with members of PLWHA groups from different regions of Thailand. In total, nine groups in the North (in Chiang Mai and Chiang Rai), three in the Northeast (Khon Kaen and Nong Bua Lamphu), and two in Bangkok were visited and informal interviews conducted with members and group organizers. On occasion, follow-up interviews allowed for more in-depth discussion both in group situations and with individual members. In addition, coordinating and review meetings were attended in Chiang Mai, Bangkok, and Khon Kaen, and these afforded the opportunity to talk with both PLWHA leaders from a larger number of groups and non-governmental organization (NGO) and local government officials working with coalitions of PLWHA groups.

2. It is important to note that the social impact of HIV is constantly evolving; the cultural and social dynamics I consider here are relevant to a certain time period. While their specific forms may change, the described responses to HIV and AIDS are part of an ongoing process in which individuals and larger levels of the Thai social order come to terms with HIV and AIDS.

3. Sentinel surveillance is organized HIV testing carried out annually by the Ministry of Public Health amongst select groups throughout the country (in the past it was conducted every six months). See Lyttleton (2000) for details of its history and group selection.

4. Explosive spread had been detected amongst injecting drug users a year earlier, but this was not perceived to hold the same threat to the general population (Yaowarat, Pramarnpol, Athibodhi, and Bernhard 1996:25).

5. While affected and infected children themselves form a constituency enormously subject to the devastation of AIDS in Thailand, I do not consider them directly in this article.

6. In drug users, rates have also recently risen again, but such findings have garnered less public attention and policy action (World Bank 2000).

7. While male sex workers form one of the sentinel surveillance target groups in Thailand, testing takes place in a limited number of urban centers and though not minimal HIV seroprevalence has consistently ranked lower than amongst female sex workers. Estimates of relative homosexual and heterosexual levels of infection (amongst sex workers) are muddied by some male sex workers self-identifying as heterosexual. Epidemiological summaries break down the HIV infected population into either sexual or needle based transmission and male or female levels of infection. In my discussion I focus on issues of gender in PLWHA groups rather than sexuality per se.
8. For example, despite advances in behavioral interventions and treatment in the United States, "in 1996 annual AIDS incidence and mortality for men dropped 8% and 26% respectively, while for women incidence rose by 1% and mortality dropped by only 12%" (Gollub 1999:1479).

9. At the same time, it should be noted that the data I report come almost exclusively from members within these groups that is, individuals who have chosen this route of normalization and who constitute an uneven cross-section of those with HIV. Their narratives and responses to my questions inevitably reproduce the normative elements of belonging to PLWHA groups and thereby form the focus of this article, which, ipso facto, does not cover the experiences of a broad spectrum of HIV infected who have not joined groups.

10. Cameron and Lee (1999) provide an analysis of a sample of AIDS service organizations in the U.S. and their evolution from supporting a constituency largely comprised of gay men to having to cater to the needs of a growing heterosexual population (consisting mostly of women). Their study, however, considers the distinctions across a sexuality, rather than a gender, divide.

11. While gender strongly conditions the direction of care and support given within families, men do at times assist female relatives. One recent study of a small sample of HIV-infected widows in North Thailand showed that roughly 20 percent of respondents "felt their fathers and brothers were available for support" (Dane 2002:194).

12. In 1999 the average cost of treatment for someone who had died of AIDS was the equivalent of $1,200 (Wassana and Suwannarat 2002:19).

13. NAPAC (the Thai-Australian Northern AIDS Prevention and Care Project), begun in 1994, provided the impetus for many groups. It was initially directed by prominent Thai social commentator Dr. Seri Phongpit, who was hugely influential in stressing the benefits of public disclosure and in providing grassroots assistance for the formation of PLWHA groups.

14. In mid 2001 a similar sequence of (still unfolding) events has taken place in Samut Prakan near Bangkok, where a pharmacist (also named Mor Wichai) who sold V1 Immunitor as a supposed AIDS "miracle cure" again riveted attention from both PLWHAs and health authorities, who banned its sale pending further studies. A joint Thai-Chinese project is also researching the anti-retroviral properties of groups of five herbal plants. Phase 3 testing was scheduled to begin in Chiang Mai in 2002.

15. Access to medical treatment is facilitated enormously by the organized liaison between PLWHA groups and government health services, outside these networks treatment is at times less readily accessed, as the World Bank notes "There is limited but disturbing evidence that many, if not most PLWHAs are not currently reached by cost-effective prevention treatment and care programs for opportunistic diseases" (2000:24).
16. Yoshioka and Schustack (2001) also point to the “collectivist orientation of Asian communities” and to “cultural values of harmony and avoidance of unpleasant interaction” in their discussion of disclosure patterns of HIV-infected Asian-American gay men.

17. One PLWHA group leader, somewhat ironically, also described his life as a soap opera because of the intense public profile nowadays accompanying the emotional highs and lows of being positive in Thai PLWHA groups.

18. See, for example, Dunbar, Mueller, Medina and Wolf 1998, who record similar sentiments from women with HIV in the U.S.

19. Effects of previous behaviour, karma, do play a part in traditional beliefs concerning illness and disease causality (see Mulholland 1979). While some PLWHAs whom we interviewed suggested that, these days, due to an appreciation of the biological nature of virus transmission, karma is far less consciously evoked in any causal sense, it nonetheless continues to underpin the appreciation of one’s overall life trajectory and appears as a theme in many published diaries kept by those with HIV (see, for example, Seri 1996). It is also evident in the increased merit-making undertaken by some with HIV.

20. Recent changes in international drug production protocols and Thai MOPH (Ministry of Public Health) policies allowing generic manufacture and compulsory licencing mean that a growing number of Thai PLWHAs will have increased access to cheaper antiretrovirals. Debate is currently taking place as to what drugs the government will produce, their price, and whether they will be covered by the national health plan. In late 2001 the Thai government was providing antiretroviral medication to only 3,000 Thai PLWHA, but the Ministry of Health pledged to increase this to 23,000 by the end of 2002 (Thai NGO Coalition on AIDS 2002b), although numerically this was still less than five percent of the total 700,000 estimated to have HIV.

21. Many PLWHAs told us how coming out had also dramatically broadened their social horizons. One PLWHA noted, “Now local politicians wai [greet with deference] me first, I converse with doctors as peers, I travel locally and go overseas, all because of AIDS.”

22. The demographic impact of this differential is indicated by a recent study showing a life expectancy decrease of ten to thirteen years for young boys, compared with five years for young girls in the northern provinces (van Griensven, Surasiangsunk and Panza 1998).

23. Singhanetra-Renard, Chongsatitmun, and Aggleton (2001:171-172) comment that, in Thailand, testing has been utilized predominantly as an epidemiological modeling tool rather than as an individualized prevention activity whereby knowledge of HIV status and appropriate counseling act as a means of lessening transmission. Consequently, many people see no benefit to being tested.
24. The converse would, of course, appear equally true; that is, a female orientation will/should encourage female membership. But this rarely appeared as an explanation, which simply highlights how, with regard to issues of gender and sexuality, Thai women’s experiences are commonly framed in terms relating to men’s behaviour and understandings (see also Knodel, van Landingham, Saengtienchai, and Pramualratana 1996).

25. This characteristic is also used by PLWHAs to explain why fewer men than women are carers, a trend not unique to Thailand.

26. While there have been some self-forming support groups specifically for injecting drug users, they have had a difficult time sustaining operational support and membership.

27. Roughly one million women become pregnant each year in Thailand. Levels of close to two percent HIV sero-prevalence among this group mean that, each year, many thousand women learn of their infection during routine antenatal treatment. It has been estimated that, during the late 1990s, approximately 23,000 HIV positive women give birth annually (Bennetts et al. 1999:738; Chomnad et al. 1998:57), although these reports don’t mention how many choose or are persuaded to have abortions.

28. In mid-2001 a Web-based chat board was established by a female master’s graduate who had recently learned of her HIV infection. The site, which is based on her regular diary postings, has been enormously popular, and print editions of her writings have recorded tremendous sales.

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