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**Living with HIV/AIDS in Thailand: Results from a  
Self-administered Survey**

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**Living with HIV/AIDS in Thailand:  
Results from a Self-administered Survey**

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## ABSTRACT

Survey data collected during 1999 and 2000 of 424 young adults with HIV and/or AIDS (PHAs) recruited primarily from support groups in northern Thailand and Bangkok explore symptoms, treatments, care taking arrangements, migration history and plans, and community reaction. Seventy one percent of the entire group report receiving some type of modern treatment or “western medicine.” Among those reporting HIV related symptoms, men are more likely to receive treatment and modern treatment than are women, but not when the analysis is limited to those reporting at least one of the most serious outcomes. Little difference was found in access to treatment across our categories of socioeconomic status. Use of specific conventional treatments used in the west, such as anti retroviral therapy, treatment of opportunistic infections, and palliative care are rarely reported by this sample in response to an open ended question about types of modern treatments received. Herbal remedies and meditation are commonly reported. Two thirds of the group report total expenditures for treatment to be less than \$125. The government health card insurance program is reported by 40% of those residing outside of Bangkok as their major source of medical payment. Mothers play key care taking roles for many of the unmarried, and are expected to play major care taking roles for many married and unmarried PHAs in the future should the health of the PHA worsen. Community reaction is variable, but is generally reported as less favorable towards men, Bangkok residents, and those at the extremes of the socioeconomic spectrum. Implications of the findings for the anticipated expansion of treatment protocols are discussed.

Key words: AIDS; migration; care giving; treatments; community reaction; stigma

## EXECUTIVE SUMMARY

Treatment protocols for persons with HIV and/or AIDS (PHAs) in developing countries will undergo profound changes during the next few years. Drugs already in widespread use in the west for the most common opportunistic infections (OIs), palliative care, and the bolstering of the immune system will be much more widely deployed in countries like Thailand that have the resources and the health infrastructure to implement these changes.

Many PHAs will benefit from these changes. According to preliminary results from the 2000 HIV/AIDS Projections, out of a population of 61.3 million, 984,000 adults and children have been infected with HIV in Thailand since the start of the epidemic and 289,000 of these people have subsequently died of AIDS (The Thai Working Group on HIV/AIDS Projection 2000). This leaves nearly 700,000 persons currently living with the virus in this country alone. Yet basic information about the types of treatments currently taken by the vast majority of PHAs who are neither involved in drug trials nor currently hospitalized, and the range of care taking arrangements for them, is very poorly developed. This report attempts to expand this important database of information.

The report is based on a survey of 424 Thai PHAs and explores a number of dimensions of their experience with HIV and AIDS, including health condition and symptoms, current treatments, living arrangements, migration history and plans for future moves, and perceptions of community reaction. The data were collected in 1999 and 2000. Respondents at the time of data collection were living in areas having some of the highest prevalence rates in the country: Lampang, Chiang Mai, and Chiang Rai provinces located in the northern part of the country, and Bangkok. Most were recruited from PHA support groups. These data provide much broader coverage of the PHA population than do those based upon clinical trials or other special populations such as military personnel. In fact, we believe our approach to be the best possible source of information about PHAs in a country such as Thailand that does not have an extensive database of PHAs such as exist in the U.S. and other countries where the advantages of disclosure of HIV status are much higher than they currently are in Thailand.

The vast majority of this sample of PHAs report HIV related symptoms but only a few have experienced severe mobility impairment that would prevent them from participating in such a study. Eighty four percent received some type of treatment related to HIV infection, and there was wide range of types reported. Seventy one percent of the entire group report receiving some type of modern treatment or "western medicine." Among those reporting HIV related symptoms, men are more likely to receive treatment and modern treatment than are women, but not when the analysis is limited to those reporting at least one of the most serious outcomes. Little difference was found in access to treatment across our categories of socioeconomic status. Use of specific conventional treatments used in the west, such as anti retroviral therapy, treatment of opportunistic infections, and palliative care, are rarely reported by this sample in response to an open ended question about types of modern treatments received. Herbal remedies and meditation are commonly reported.

Treatments undertaken do not appear to lead to overwhelming financial outlays among these PHAs. Two thirds of the group report total expenditures for treatment to be less than \$125. Widespread participation in the government's health care service program likely keeps medical outlays by PHAs and their families much lower than they would be otherwise. Differences in amount spent by sex of the PHA are not statistically significant, but we do find that members having jobs outside of agriculture and the unskilled sector are more likely to spend over \$250 on treatment costs than their less privileged counterparts. But even among the higher status members of our sample, very few have spent vast amounts on illness related expenses.

Spouses and mothers play key care taking roles for these PHAs. Moreover, across our major categories of interest, mothers are the most consistently reported anticipated care giver for the future, when the PHA's health can be expected to deteriorate. Spouses and family members other than parents are also expected by many respondents to play major care giving roles in the future. Such care giving concerns have led to changes in residence for many of these respondents, as have increasing needs for financial support, help with raising children, and psychological support. A fifth of those who had mothers healthy enough to care for them but who were not currently living close to their mothers reported that they plan to move in with them should their health worsen.

Community reaction as reported by the PHAs ranges widely. Sympathy and active support, contempt and fear, and no reaction at all, are all reported by significant proportions of respondents. Provincial PHAs and women perceive much more positive community reaction than Bangkok residents and men. Those in the middle education category generally have more favorable experiences with community reaction compared with those less well off and those more privileged.

Anticipated expansion of treatment protocols must take into account these variations in the degree of community acceptance of PHAs. While the availability of more effective treatments will increase the motivation of PHAs to self disclose, negative community reaction must also be confronted where it exists, especially for men, Bangkok residents, and those at the two extremes of the socioeconomic continuum. The widespread use of herbal remedies must also be taken into account since some of these remedies may interact with western drugs. Parents of PHAs, especially mothers, warrant special attention both to their needs and to their potential, since it is they who are providing much of the current care to these PHAs, and it is they who will be called upon to provide more intensive care in the future, both for these respondents and for many more like them. Parents, especially mothers, may hold the key to the success for future efforts that require careful monitoring of dosage and timing of the multiple drug regimens that Thailand is now considering.

## INTRODUCTION

Persons with HIV and/or AIDS (PHAs) face a myriad of problems and issues related to their infection. That most of the academic literature to date focuses on the fairly unique situation of PHAs living in the U.S. and other western countries belies the fact that the vast majority of those infected live in the higher prevalence countries (HPCs), all of which are found in the developing countries of Africa, Latin America, and Asia. Moreover, the nature of the problems PHAs face in HPCs will be quite different from those problems faced by their counterparts in the west.

One key dimension of this difference involves the ways and the degree to which a PHA's family is affected by his or her illness. While certainly families of PHAs are also affected in the low prevalence countries (LPCs) of the west, impacts of AIDS on HPC families are more common given the higher levels of prevalence; more intense given the much higher levels of mutual dependence between generations; and different in kind given the distinct patterns of co residence, care taking, and belief systems about AIDS and health found there. HPC families are in fact affected during all stages of PHAs' experience with HIV. Decisions about HIV testing have critical implications for spouses, since marital transmission is a major conduit for HIV in most HPCs. For those testing HIV positive, PHAs must contend with not only the psychological issues of coming to grips with such a serious, and in some cases, stigmatized illness, but must also begin to plan for the future of his or her dependents. This is because unlike in the west where anti retroviral and highly active anti retroviral therapy (ART and HAART) are in common use and make long term survival possible, therapies that actually combat the deterioration of the body's defenses are currently beyond the reach of all but a tiny fraction of PHAs living in HPCs like Thailand. (World Bank 2000). For PHAs in HPCs already suffering from AIDS-related symptoms, care taking and payment for treatments for the illnesses and symptoms associated with HIV will much more likely involve the family than PHAs seeking similar treatments in the west, given the greater extent of mutual dependence between generations and the lesser extent of institutionalized health care and health care payment schemes.

Research on how HPC families are affected by AIDS is sparse. Some conceptual treatments of the impacts of AIDS on the family have focused on Africa (Palloni and Lamas 1990) and Thailand (Boonchalaksi and Guest 1993; VanLandingham et al. 2000), but the empirical data needed to address specific problems PHAs and their families face in HPCs are only just emerging. Research related to the survey discussed in this report has found that coresidence and care taking responsibility for PHAs very often involve their older parents. A study of key informants (primarily local health center staff) about the cases in their local areas found that two-thirds of the adults who died of AIDS either lived with or adjacent to a parent by the terminal stage of illness; a parent, usually the mother, acted as a main caregiver for about half (Knodel et al. 2000). This report will address some of these same coresidence and care taking issues from the perspective of the PHA, along with current sources of economic support, and future migration plans among the PHAs in our sample.

Little is known about the types of treatments PHAs participate in (except for the tiny fraction involved in drug trials); to what extent they combine conventional treatments for AIDS-related symptoms and opportunistic infections with HAART and/or indigenous remedies; who pays for these treatments; and how much they cost. Addressing such deficiencies regarding what we know about the treatment status quo has become imperative since it seems virtually certain that Thailand along with other middle income countries will be implementing an expansion of the treatments available to PHAs in the near future. These major changes require baseline knowledge of the range and extent of treatments PHAs currently undergo. Nearly all research on treatments of PHAs in developing country settings focus on the subjects of clinical trials. Such trials provide essential information about how well specific regimes perform, but tell us little about PHAs who do not benefit from the intense scrutiny and medical supervision that such trials provide.

Part of the reason for this deficiency in the literature regarding treatments is due to the difficulty involved in recruiting an appropriate sample. Population based studies of treatments are hampered by the

fact that the vast majority of PHAs who are not involved in drug trials are a difficult group to access. Many are not in contact with the formal health system until they reach very advanced stages of illness, and anecdotal evidence suggests much use of informal treatments that are prescribed and administered by family and others operating outside of the formal health sector (VanLandingham 2000). Yet it is critical to understand as well as possible the range and frequencies of current treatment strategies for several reasons. First, it is important to know how well the formal health infrastructure is delivering basic care to PHAs before it can be known what steps are needed for expansion. Second, it is important to know the range and frequency of use of nonstandard treatments, since traditional drugs may interact with western medicines. We know that the use of such traditional and nonstandard treatments are popular in the west (Lubeck et al. 1996), and they are likely to be even more widespread in poorer countries such as Thailand where access to effective but expensive anti retroviral drugs is so much more limited. Some work has begun to focus on the prevalence of traditional treatments in Africa (e.g., Kabambe 1998) but is limited to extremely small and selective samples.

Third, it would be useful to have some idea of the amounts of money PHAs and their families are paying for current regimens in order to better estimate how much families might be willing and able to contribute to the costs of new and better treatments.

One final topic of importance regarding the plight of PHAs and their families is that of social stigma. Assumptions based upon anecdotal evidence are much more common than systematic investigations. Other components of this project examine this topic from the perspective of health care administrators and providers, community leaders, and the parents of PHAs. This paper will report perspectives on community reaction from the PHAs' perspective.

## **BACKGROUND**

Thailand is experiencing a serious AIDS epidemic with prevalence levels much higher than those found in the United States, but much lower than those found in the hardest hit African countries.<sup>1</sup> Careful and extensive sentinel surveillance since the onset has resulted in the Thai AIDS epidemic being one of the best documented in the world (World Bank 2000). The earliest groups to suffer widespread infection were intravenous drug users and commercial sex workers. Until recently, many of the men who patronized these sex workers did so without the protection that condom use provides, and consequently the virus rapidly spread among young men. From there, many of these HIV-positive men went on to infect women not involved in the commercial sex trade, i.e., their wives and girlfriends (Brown et al. 1994; Weniger et al. 1991). According to preliminary results from the 2000 HIV/AIDS Projections, out of a population of 61.3 million, 984,000 adults and children have been infected with HIV in Thailand since the start of the epidemic and 289,000 of these people have subsequently died of AIDS (The Thai Working Group on HIV/AIDS Projection 2000). This leaves nearly 700,000 persons currently living with the virus in this country alone.

While exact numbers and projection trends are subject to contention, it is generally agreed that incidence has peaked and will continue to decline for the foreseeable future. This is due at least in part to the success of Thailand's efforts to implement a 100% condom policy for commercial sex transactions (Chamrathirong et al. 1999), and perhaps also by aggressive campaigns to treat other sexually transmitted diseases that facilitate the spread of HIV (Hananberg et al. 1994). Increasing fears among young men about the dangers of commercial sex patronage have also undoubtedly played a major role (VanLandingham and Trujillo 2000; UNAIDS 1998a; UNAIDS 1998b; Mills et al. 1998; Knodel et al. 1996). Even with these dramatic declines in the rate of new infections, barring a dramatic medical breakthrough large numbers of HIV persons will be developing AIDS-related symptoms during the next two decades.

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<sup>1</sup> Hereafter we refer to the HIV/AIDS epidemic as the AIDS epidemic. For current infection rates for Thailand and other countries, contact the website for UNAIDS: [www.unaids.org](http://www.unaids.org).

Prevalence currently varies widely by region, and are highest in the northern part of the country, followed by the southeastern seaboard. HIV prevalence rates among pregnant women have ranged from over 10% in some northern provinces to less than 1% in some central, northeastern, and southern provinces.<sup>2</sup> Prevalence levels along the southeastern seaboard have risen rapidly in recent years and are now intermediate in level (UNAIDS 2000).

## **METHODS**

### **Site Selection**

Study sites include Chiang Mai, Chiang Rai, Lampang, and Bangkok. These sites were chosen because of their generally high prevalence levels and because they can help illustrate key differences between the urban Bangkok situation and the provincial north.<sup>3</sup> While we wished to include other areas having emerging epidemics, we found the recruitment issues to be too difficult. Organization of support groups for those infected was a key factor in our choice of sites, since this provided a mechanism for identifying and selecting PHAs for the study. Choices of PHA groups were based upon personal contacts with leaders of these groups.

### **Populations of Interest, Sampling Procedure, and Data Limitations**

The ideal sample for a study such as this from a purely theoretically point of view would be a random sample of all PHAs in Thailand. Such a sampling strategy is unfeasible for a number of reasons. First, many PHAs are unaware of the fact that they are infected with HIV, and those who are aware are likely to be systematically different from those who are unaware on a number of key aspects related to the outcomes of interest. For example, married women who are HIV positive and who become aware of their HIV status by agreeing to undergo HIV testing during antenatal care are likely to be quite different on average from otherwise similar women who decline testing, in terms of their sexual behaviors and social relationships.<sup>4</sup> HIV positive men who become aware of their status via treatment of associated OIs will on average have been infected for a longer duration, may have reached a different stage/level of acceptance of their HIV status, and will have thought more about their future plans than infected men who are unaware of their HIV status.

Second, infected persons who join support groups for PHAs will likely be systematically different in important respects from those who do not join. PHA group members may benefit from psychological support of other PHAs; are more likely (at least for the groups sampled for the current study) to be female than male (even though the population of PHAs is heavily weighted towards males); may benefit from experimental or other special treatments that the group negotiates; are on average likely to be more open regarding their HIV status compared to non-joiners; and are more likely to live in areas (usually high prevalence urban centers) that have their own unique characteristics.<sup>5</sup> Another problem concerns the extent to which PHAs are actually able to anticipate their future care taking and co residence decisions and how their community will deal with them throughout their illness. For example, decisions to move,

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<sup>2</sup> The median infection level among sites where pregnant women were tested was 1.3% for sites in Bangkok and 1.7% for sites outside of Bangkok in 1997 (UNAIDS 2000). Mortality statistics show a marked increase in the age-specific-death rates of adult men between 1990-1996. The death rate for men age 25-29 has increased most significantly in the North region and this increase is due to AIDS (Im-em 1999; van Greinsven et al. 1998).

<sup>3</sup> HIV prevalence among military recruits for the period November 1991 through May 1998 is 8.3% for Chiang Mai; 5.4% for Lampang; 9.4% for Chiang Rai; and 2.7% for Bangkok (Im-em 1999).

<sup>4</sup> Voluntary counseling and testing programs have been in place since 1995 (World Bank 2000), but participation and refusal rates of such programs could not be located.

<sup>5</sup> Not all high prevalence cities have PHA support groups, e.g., Rayong did not have such a group at the time of our preliminary fieldwork there.

e.g., to move home to be with parents, may be made fairly spontaneously, especially if they occur near the end of the PHA's life; treatment costs and community reaction may also change as the PHA becomes very ill. To put the issue in demographic parlance, a PHA's experience with living arrangements, treatment costs, migration, and community reaction is censored until he or she dies, so studying PHAs who are still alive could, for example, bias estimates of migration downwards if much migration is delayed until near the end of life.

Major advantages of studying PHAs in support groups are that they are generally accessible through the group; are often highly motivated to participate in AIDS-related research; are healthy enough to participate (if they are healthy enough to attend the groups' meetings); and they have often had structured opportunities to think about what actions they will take in the future should their health deteriorate.

Keeping in mind the potentially serious issue of representativeness, data from our sample of PHAs provides insights into care taking arrangements, treatment regimens, and future plans that at least some subset of infected persons share. Most importantly, we believe our sampling procedure to be the best currently available to gain access to a broad range of PHAs in Thailand who are still well enough to participate in such a project. Registries of PHAs that cover a substantial segment of the PHA population such as exist in developed countries like the U.S. do not exist in Thailand. This could change if the benefits of disclosing one's HIV status increased, e.g., if better drug treatments became available to those infected or if special welfare payments to PHAs and their families became more widely available. Until such registries become available, we believe our approach to be the best currently available to investigate these important issues, all of which have immediate and important policy implications for programs targeting PHAs and their families.

## **The Instrument**

The PHA questionnaire is included as an appendix. One objective of the instrument is to assess current and anticipated living and care taking arrangements, including future plans for a change in residence. We are particularly interested in assessing the role of the PHA's parents in care taking. An assessment of current symptoms and treatments are included primarily as control factors to help assess care taking and coresidence differentials; however, since data on these topics *per se* are so sparse we also treat these variables as outcomes of interest in and of themselves.

Questions 1-27 assess important background characteristics of the PHA, focusing on the living status, and the location and health status of parents. These questions will help us to assess the availability of parents for care giving to the PHA and/or her children. Questions 28-34 inquire about the symptomology, current treatments, and general health status of the PHA. The purpose of this section is to establish what stage of the disease the respondent is in so that we can assess at what stage of the illness parents of PHAs typically become involved. Questions 35-44 are included to assess current living and care taking arrangements for the PHA, and the level and the sources of resources used to pay for the PHA's living and care taking expenses. Questions 45-54 assess past moves and plans for future moves in response to the PHA's illness. This section asks about moves by the PHA as well as moves by others in response to the PHA's illness. The final set of questions assess community reaction to PHAs from the PHA respondent's point of view.

The final instrument was the result of two sets of pretests conducted early in 1999. The final version was conducted between March and August 1999 for Chiang Mai, Chiang Rai, and Bangkok, and during October 2000 for Lampang.

## **Recruitment and Administration**

Lampang participants were recruited in the following manner. One of the principal investigators for our broader project contacted nurses who currently work in two community hospitals and an official at a district public health office. These intermediaries were briefed on the project objectives and instrument

administration. The intermediaries in turn recruited a total of 100 participants, most of whom participated as part of their PHA group meeting, but a few of whom were contacted at home. One of the PHA groups was based at a hospital in a rural area of the province and one was based at a hospital in the town. In Chiang Mai, about half of the respondents were members of a local PHA support group who filled out the questionnaires during a regular meeting of their group. The other half were patients at a district level hospital and local health stations. In Chiang Rai, a trained research assistant and his assistant distributed the questionnaires to PHAs attending support group activities. Bangkok participants included members of a PHA support group as well as individuals recruited through the personal contacts of one of our research assistants.

The usual administration procedure was assisted self-administered, which involves a central person reading and explaining the questionnaire to an assembled group, with several assistants in the audience to answer questions and/or assist confused respondents. These assistants were thoroughly briefed about the content and purpose of the study beforehand. Other respondents answered the questionnaire on an individual basis, but could ask our contact at the PHA group, our research assistant, or our local contact for clarification.

Questionnaire administrators received detailed instructions regarding questionnaire procedures. There were no significant problems reported with its administration. In Chiang Rai, 2 of the 100 participants invited to participate were unable to complete the questionnaire because they were ill. In Chiang Mai, there were also 2 intended participants attending the meeting who were too ill to participate, and 2 others who did not want to participate for reasons that were unclear. In Bangkok, there were 13 refusals due to reasons of shyness (3), unwillingness to participate because of lack of adequate compensation (3), not believing that they were HIV positive (3), and other unknown reasons (4). In Lampang, there were no refusals.

## RESULTS

Background characteristics of the PHAs in our sample are presented in Table 1. Our 424 respondents were split fairly evenly among the 3 provinces and Bangkok. The median age is 31 years. Two thirds of our respondents are women, which is quite different from the national sex distribution of cases. Women make up only 31% of the caseload in Thailand in 2000 (Thai Ministry of Public Health 2001). Farmers and laborers make up two thirds of the occupations reported by our respondents; these reported occupations are of course seldom reported for the Bangkok respondents. The most common occupations reported for the Bangkok respondents are hair dresser (7%), construction labor (6%), student (6%), housewife (5%), company employee (5%), and small enterprise (5%). Almost 2/3 of the respondents report current rural residence and just over 3/4 report a rural upbringing. The proportion of the entire Thai population living outside of urban areas in 1998 was 79%, according to the UN Population Division (cited in UNAIDS 2000).

Distribution of marital status varies with both sex and province. Overall, a third of the male PHA sample is never-married, but only 2% of the women are. Also, single men make up higher proportions of the samples in Chiang Mai and especially in Bangkok compared to Chiang Rai and Lampang. High proportions of the female sample are widowed (62%). Among the widowed women, 91% know or suspect that their former husband had AIDS. Overall, 89% of the ever married report that their partner was also infected with HIV. Seventeen percent of the sample coreside with a parent, with wide variance on this measure among the sites.

Various measures of the HIV and health status of our respondents are reported in Table 2. These measures are included to help us assess what stage of illness the individual respondent is in, so that we can examine its influence on care taking and co residence patterns. These relationships are explored in Table 5. The first item in Table 2 confirms that nearly all of the respondents acknowledge that they are HIV positive, which is expected since most were recruited from PWA groups. Ninety percent report ever having HIV-related symptoms, and of these, 95% report currently having symptoms. Just over two thirds

of those ever experiencing symptoms have had them for a year or more. These data suggest that individuals joining these groups do so when they begin to experience some of the health effects of their illness. Women appear more likely to join before they have symptoms than are men, since fewer of them have ever had them (87% of women versus 96% for men); this may be due to some female PHA group members discovering their HIV status early as a result of antenatal care. Only 28% of the PHAs report themselves to be in excellent or good health. Men PHA respondents report themselves on average to be in poorer health than do the women, but not at a statistically significant level.

The types of health problems reported by this group of PHAs are variable. Fever, headache, weight loss, rashes, and tiredness/exhaustion are each reported by half or more of the sample. More men report experiencing each symptom asked about than women except for headache, which is about the same for both men and women. More than 10% report the fairly serious limitations of having difficulty moving about and being unable to work; but only 5% or less report the most serious loss of independence that would probably preclude their participation in the activities of the PHA group and the study, i.e., being unable to walk, dress themselves, or leave the house alone.

Table 3 presents tabulations of who received treatments for their HIV-related symptoms, and what kinds of treatments, by province of residence, socioeconomic status, and sex. Eighty four percent of the entire sample had received some sort of treatment for HIV related conditions. Men are statistically significantly more likely to receive both any treatment and modern treatment than are women. These sex differences are maintained when conditioned on ever having had at least one of the symptoms listed in Table 2, but not when conditioned on ever having reported at least one of the most serious outcomes, i.e., having had difficulty moving, or are unable to work, walk, leave the house, or dress themselves (n=73; results not in table). Differences in proportions receiving any treatment and modern treatment by educational category are small and statistically insignificant.

Very few of the sample report receiving anti retroviral therapy (7%), TB treatment or prophylaxis (7%), treatment for other OIs (9%), or even treatment for pain or symptom relief (6%). While this is very disturbing given the high proportions reporting symptoms in Table 2, it is possible that respondents underreport specific treatments in an open ended question format.

Use of herbal remedies, reported by 30% of total sample, is very common in Chiang Rai province (62%), and reported more frequently among those in the low and middle education categories than in the high category (p=0.05). Bitter cucumber and green chiretta were the most frequently specified. Use of meditation as a treatment is reported by 30% of the Chiang Mai respondents.

As shown in Table 4, few of the respondents report spending large amounts of money for treatment-related expenses incurred because of their HIV-related health problems.<sup>6</sup> Just over ¾ of the sample report spending a total of less than 10,000 baht (about \$250); just under 2/3 report spending less than 5000 baht (about \$125), which is less than 5% of the 1997 GNP per capita of \$2740 (World Bank, as reported in UNAIDS 2000). Men and women do not differ dramatically on the amount spent, but the highest categories for amount spent include more men than women. With total amount spent split on either above/below B5000 or above/below B10,000, sex differences in amount spent are statistically insignificant.<sup>7</sup>

The absence of large differences among our educational attainment categories (a proxy for socioeconomic status) in reported spending is interesting. We divide educational attainment into three levels: low education = less than 6 years of education (37% of the sample); middle education = 6 years of education (36% of the sample); high education = more than 6 years of education (27% of the sample). The middle education group has the highest proportion reporting expenses below 10,000 baht (84%); the low education group the second highest (76%) and the high education group, as would be expected, the lowest proportion (73%). In addition to the small differences in spending among these social categories,

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<sup>6</sup> Expenses include those for medicines and other treatments, transportation, food and housing costs related to treatment for both the PHA and accompanying family members.

<sup>7</sup> Controlling for health card possession (see below) makes no difference in this calculation.

it is also surprising how few in the most privileged educational group spend large amounts on their illness. Proportions spending more than 50,000 baht do not differ much among the three groups.

Using occupation as a proxy for socioeconomic status is difficult given that so many of the respondents work in agriculture or in jobs utilizing unskilled labor. But a category combining all other occupations, including skilled laborers, factory workers, students, and those working in business, sales, and the professions, makes up about a fifth of the sample. This division by occupational groups (agricultural and unskilled labor versus jobs requiring higher skill) does lead to statistically significant differences in amount spent, with a third of this high occupation group spending 10,000 baht or more on treatment versus only a fifth of the lower occupational group. Still, only 7% of this high occupation group spend 50,000 or more (results not in table).

The infrequency of substantial sums being spent on treatment is likely due to a number of factors. First, HAART is available only to a tiny fraction of the PHAs in Thailand, as is the case in most other HPCs. Second, being a member of a PHA group may also provide some protection against spending large amounts of money on expensive but ineffectual treatments since these groups usually have an educational and advocacy component to them. Third, most of our respondents are still healthy enough to attend at least occasional PHA meetings; costs may increase as their ailments worsen. However, we find very little difference in the amounts spent by those who have had symptoms for more than a year compared to those with more recent onset (results not shown). Fourth, the very rich may be less likely to join such groups since a major function of the group is to provide opportunities for social interaction. Fifth, government health insurance is widely available through the purchase of a health card (*baht sukopab*). Purchase of the health card provides unlimited access to the extensive network of government health clinics and hospitals for a family of five for a yearly fee of 500 baht (approximately \$12.50).<sup>8</sup> Sixty-two percent of this sample of PHAs who had ever received treatment had a government health card, with women, the middle and low education groups, and provincial northern residents disproportionately represented relative to men, the high education group, and Bangkok ( $p=0.000$  for all three comparisons).

As seen in the next item in the table, women, respondents in the low and middle education categories, and non-Bangkok residents are also the most likely to report the health card as the primary source of medical payments for their HIV/AIDS related symptoms, among those ever receiving AIDS related treatments. The health card was cited by about 1/3 of the respondents overall as the principal source of these medical expenses; this rises to 40% for those residing outside of Bangkok. The PHA himself or herself was also cited by about 1/3 as the primary payee. Parents were cited by about 10% of the cases. Friends, insurance offered by the workplace, insurance bought privately (not shown), and the government social welfare each accounted for 1% or less of the responses. When asked to name all sources contributing to these expenses (results not in table), government social welfare, private or workplace-offered insurance were still cited by less than 3%. While we don't know the proportion who had their fees waived, staff we interviewed at least one hospital said that they routinely waive the fees for PHAs coming in for treatment if they do not have a health card and otherwise cannot pay (VanLandingham 2000).

Duration of symptom experience is used as a proxy for stage of illness in the tabulations presented in Table 5. The primary purpose of this table is to examine the relationships among marital status, how ill the PHAs are, and who takes care of them. Unmarried respondents obviously cannot rely upon spouses for care giving, thus the percentages cited for other types of major caretaker will necessarily be higher. Relying upon oneself, other family, and one's mother are the most frequently cited among this unmarried group. The relative importance of other family members (i.e., not parents) and oneself relative to mothers appears to increase for the unmarried as their illness progresses, a finding not readily explicable and at odds with results from our other data. We find a fair amount of migration among PHAs to their parents' home at late stages of illness (Knodel 2001), and qualitative reports from parental care givers and from our key informants indicate frequent and intense parental care giving (especially by mothers) to infected

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<sup>8</sup> One PHA group we visited in Khon Kaen provided health cards as a membership benefit.

children as their symptoms worsen (Saengtienchai and Knodel 2001; VanLandingham 2000). This inconsistency is likely due to the fact that our most of our sample of PHAs for this study, even those experiencing symptoms for more than a year, are still healthy enough to be attending PHA meetings. The importance of mothers most likely will not manifest itself for those in such a sample, since, as discussed in the methods section above, their experience with care taking is in most cases limited to the early stages of illness.

If we restrict tabulations to those unmarried PHAs whose mothers are both alive and deemed able to care for the PHA if the need arose, unmarried PHAs citing mothers as principal care giver rises from 23% (Table 5) to 53% (results not in table), but the negative association between symptom duration and the tendency to cite mothers as the principal care giver remains. For the married, spouses are by far the most frequently cited as the primary care giver, especially among those who have been ill a year or more.

The bottom half of the table reports responses to a question about anticipated care givers should the PHA's health deteriorate; the PHA himself or herself is removed as an option. Mothers and other family members are seen to be the most probably choices among the unmarried; spouses and mothers among the married. These results suggest that these PHAs have given thought to what sort of care taking arrangements are likely for them in the future; moreover, these answers are consistent with other data we have collected about cases in the final stages of illness, i.e., cases who died.

Migration history and plans among the PHA respondents are presented in Table 6. Fifty-nine percent did not grow up in the household in which they currently reside, rising to 85% of the Bangkok respondents. Twelve percent have lived in their current residence for less than a year and 32% for less than 5 years (results not in table). Among those who did not grow up in their current place of residence, 39% report that they moved there because of their HIV condition. Bangkok PHAs who did not grow up in their current residences are more likely say they returned home because of their illness than are their counterparts living in the provincial northern sites ( $p=0.002$ ). Needing help in caring for oneself is by far the most frequently given reason for moving home among those who report doing so because of their HIV condition (71%). This reason is especially high among those living in our provincial north areas of study. Just over a quarter report needing financial help, a third of the women explain that they need help in caring for their children, 21% of the women report loneliness as a reason, and 27% of the men report boredom or being disaffected (*buá*). Only 9% said that they would move in the future if their health got worse, but this proportion was three times as high among the Bangkok respondents compared to those in the northern provincial sites. Of the 50 respondents who had mothers healthy enough to care for them, but were not currently coresident with their mothers in the same household or compound at the time, 10 (20%) said that they would move if their health became worse; all 10 listed their mother as the person with whom they would move in (results not in table).

Our PHA respondents' perceptions of community reactions to them and to PHAs generally are presented in Table 7. There is a remarkably wide range of reactions to PHAs generally from the perspective of the PHAs themselves. General discussion, sympathy, support, a willingness to help, no reaction or no change in reaction, disgust, condescension, and gossip were all reported by significant proportions of the respondents (approximately a fifth or higher). Support of PHAs was the most frequently reported reaction, cited by almost half of the respondents, but there were strong differentials by sex, place, and status. Bangkok residents were much less likely to report support or sympathy as a reaction compared to our provincial northern sites ( $p=0.000$  for both comparisons). Women were much more likely to report support than men ( $p=0.000$ ) and were more sanguine about community reaction towards PHAs than men on every positive dimension we included.

To ascertain PHAs' own experience with their home communities regarding their HIV status, we first asked whether their communities were aware of their HIV status. Four fifths reported that their communities were aware that they were HIV infected; this is surely higher than for PHAs generally due to the special nature of the PHA groups that most of our respondents were recruited from. Women and provincial northern respondents were much more likely to be open about their status than Bangkok residents or men ( $p \leq 0.002$  for both comparisons). Women's more positive experiences with

community reactions compared with men's become even more sharply defined when respondents who are open about their status are asked about their own experiences. For example, 43% of the men report a community reaction of fear/disgust compared with only 29% of the women ( $p=0.02$ ). Those in the middle education category generally have more favorable experiences with community reaction compared with those less well off and those more privileged. For example, 71% of the middle education group report support as a community reaction compared with just under half for the other two education groups ( $p=0.000$ ). Bangkok residents are consistently more negative on their assessments of community reaction compared with their upcountry counterparts.

## CONCLUSIONS

This report describes the experience of 424 Thai PHAs on a number of dimensions, including health condition and symptoms, current treatments and payments for treatments, living arrangements, migration history and plans for future moves, and perceptions of community reaction. The data were collected in 1999 and 2000. Respondents at the time of data collection were living in areas having some of the highest prevalence rates in the country: Lampang, Chiang Mai, and Chiang Rai provinces, and Bangkok. Most were recruited from PHA support groups. These data provide much broader coverage of the PHA population than do those based upon clinical trials or other special populations such as military personnel. In fact, we believe our approach to be the best possible source of information about PHAs in a country such as Thailand that does not have an extensive database of PHAs. Still, there are two key caveats that must be kept in mind while interpreting the results.

First, the sampling procedure was neither national in scope nor random in application. In fact, participants by virtue of their participation in support groups are likely to be on average more open about their illness than PHAs who do not join such groups. Related to this, they are also in an earlier stage of illness than PHAs who do not join (thus allowing their participation in the groups' activities) and likely have access to more advanced treatments. Second, since the health and living situation of PHAs is likely to change substantially as their illness progresses, the fact that members of this particular sample have not yet lived through all stages of illness has advantages and disadvantages. Key advantages of participation during an early stage of illness are that this makes it possible for them to participate in a study of this type and eliminates the need for proxy reports; it serves to reduce recall bias of their activities during this early stage; and it allows an assessment of what they anticipate their future living arrangements will be. The key disadvantage is that their experience reported here is incomplete, and this early experience is likely to differ in many respects from what happens at later stages of illness. We collect information about living and care taking arrangements for PHAs who have died from proxy reports in other work related to the project, both from their parents (analysis of these data is in progress) and from local health officials (Knodel et al. 2000).

Eighty six percent of this sample report current symptoms, with a modal duration of 1-3 years. Only a small proportion report serious mobility impairment. Eighty four percent received some type of treatment related to HIV infection, and there was wide range of types reported. Approximately seven out of every ten of the entire group report receiving some type of modern treatment or "western medicine." Among those reporting HIV related symptoms, men are more likely to receive treatment and modern treatment than are women, but not when the analysis is limited to those reporting at least one of the most serious outcomes. The least privileged are just as likely to report access to modern treatment as are the better off, at least by the measures employed here. Use of anti retrovirals, treatment for OIs, and palliative care are reported by very small proportions. Herbal remedies, on the other hand, are popular.

Treatments that are undertaken do not appear to lead to serious financial outlays among these PHAs, although it must be kept in mind that those who are severely ill will not be well enough to attend the PHA meetings where most respondents were recruited. Two thirds of the group report total expenditures for treatment (including medicine, transportation, room and board, etc.) to be less than \$125. Differences in amount spent by sex of the PHA are not statistically significant, but we do find that members having

jobs outside of agriculture and the unskilled sector are more likely to spend over \$250 on treatment costs than their less privileged counterparts. Widespread participation in the government's health card program likely keeps medical outlays by PHAs and their families much lower than they would be otherwise. But even among the higher status members of our sample, who are the least likely to participate in the health card program, very few spend vast amounts on illness related expenses. Overall, we don't find great differences in the amounts spent by the most privileged in our sample compared to the less privileged, although wealthy PHAs may not join PHA support groups that form the basis of our sample.

Many of the PHAs report themselves to be their primary caretaker, but the importance of spouses for the married and of mothers for the unmarried is clear. Perhaps more importantly, the most consistently reported anticipated care giver for the future when the PHA's health can be expected to deteriorate is mothers. Mothers are frequently expected to fulfill this function for PHAs across categories of marital status, symptom duration, and sex. Spouses and family members other than parents are also expected by many respondents to play major care giving roles in the future. Such care giving concerns have led to changes in residence for some of these respondents, along with needs for financial support, help with raising children, and psychological support.

A concise summary of community reaction as perceived by these PHAs is not possible as a broad spectrum is reported. Sympathy and active support, contempt and fear, and no reaction at all, are all reported by significant proportions of respondents. Provincial PHAs and women perceive much more positive community reaction than Bangkok residents and men. Those in the middle education category generally have more favorable experiences with community reaction compared with those less well off and those more privileged.

This broad range of community response to PHAs implies that expansion of treatment protocols, both in terms of the treatments offered and the number of PHAs included, must take into account the variable community contexts of the PHAs' home communities. While the availability of more effective treatments will increase the motivation of PHAs to self disclose, negative community reaction must also be confronted where it exists, especially for men, Bangkok residents, and those at the two extremes of the socioeconomic continuum. The widespread use of herbal remedies must also be taken into account since some of these remedies may interact with western drugs. Places of distribution for these traditional remedies (such as temples and PHA organizations) may hold potential as collaborators in expanded treatment efforts. Parents of PHAs, especially mothers, warrant special attention both to their needs and to their potential, since it is they who are providing much of the current care to PHAs. They may hold the key to success for future efforts that require careful monitoring of dosage and timing of the multiple drug regimens that Thailand is now considering.

## REFERENCES

- Boonchalaksi Wathinee and Philip Guest. 1993. AIDS and Children: Prospects for the year 2000. IPSR Publication No. 168, Institute for Population and Social Research, Mahidol University, Thailand.
- Brown T, Weraset Sittitrai, Supak Vanichseni, and Usa Thisyakorn. 1994. The recent epidemiology of HIV and AIDS in Thailand. *AIDS* 8 (Supplement 2): S131-S141.
- Chamratrithirong Aphichat, Varachai Thongthai, Wathinee Boonchalaksi, Philip Guest, Churnrurtai Kanchananchitra & Anchalee Varangrat. 1999. *The Success of the 100% Condom Promotion Programme in Thailand: Survey Results of the Evaluation of the 100% Condom Promotion Programme*. IPSR Publication 238, Institute for Population and Social Research, Mahidol University.
- Hanenberg Robert, Wiwat Rojanapithayokorn, Prayura Kunasol, & David C. Sokal. 1994. Impact of Thailand's HIV-control programme as indicated by the decline of sexually transmitted diseases. *Lancet* 344 (July 23, 1994): 243-245.
- Im-em Wassana. 1999. *Mortality trends and levels to verify the AIDS epidemic in Thailand: Analysis from death registration statistics, 1984-1997*. IPSR Publication Number 239. Bangkok: Institute for Population and Social Research, Mahidol University.
- Knodel John. 2001. Return migration, residential mobility, parental assistance and AIDS: The Thai experience. Paper to be presented at the XXIV General Population Conference of the IUSSP, Salvador, Brazil, 18-24 August 2001.
- Knodel John, Mark VanLandingham, Chanpen Saengtienchai, and Wassana Im-em. 2001. Older people and AIDS: quantitative evidence of the impact in Thailand. *Social Science and Medicine* 52(9): 1313-1327.
- Knodel J, M VanLandingham, Chanpen Saengtienchai, and Anthony Pramualratana. 1996. Thai views on sexuality and sexual behavior. *Health Transition Review* 6:179-201.
- Lubeck, D, PT O'Driscoll, et al. 1996. Use of "non-traditional" treatments by persons with HIV-infection who also receive "traditional" care from primary care physicians. *Int Conf AIDS*: 1996 Jul 7-12;11(2).
- Kabambe, J. 1998. Treatment seeking behaviours in rural community. *Int Conf AIDS*: 1998;12.
- Mills S, Kumnuan Ungchusak, Vijaya Srinivasan, Budi Utomo, and A Bennett. 1998. Assessing trends in HIV risk behaviors in Asia. *AIDS*:S79-s86.
- Palloni, A., YJ Lee, and L Lamas. 1990. The effects of HIV/AIDS on family organization in Africa. Madison, University of Wisconsin-Madison, Center for Demography and Ecology.
- Saengtienchai, Chanpen and John Knodel. 2001. Parental caregiving for adult children with AIDS: A qualitative analysis of circumstances and consequences in Thailand. Manuscript.
- Thai Ministry of Public Health. 2001. Information from website (June 25, 2001): [www.moph.go.th/ops/epi/aidshtm/aidstab1.htm](http://www.moph.go.th/ops/epi/aidshtm/aidstab1.htm)

The Thai Working Group on HIV/AIDS Projection. 2000. Executive Summary - Projections of HIV/AIDS in Thailand, 2000-2020. Draft. Presented at the Siam City Hotel, Bangkok, June 30, 2000.

UNAIDS. 2000. *Epidemiological Fact Sheet on HIV/AIDS and sexually transmitted diseases: Thailand*. Geneva: UNAIDS.

UNAIDS. 1998a. *Connecting Lower HIV Infection Rates with Changes in Sexual Behaviour in Thailand: Data Collection and Comparison*. UNAIDS Case Study June 1998. Geneva, UNAIDS Best Practice Collection, UNAIDS/98.15.

UNAIDS. 1998b. *Relationships of HIV and STD declines in Thailand to behavioral change: A synthesis of existing studies*. Geneva: UNAIDS.

van Greinsven, G. J., Suwanee Surasiengsunk, and Alessio Panza. 1998. The use of mortality statistics as a proxy indicator for the impact of the AIDS epidemic on the Thai Population.

VanLandingham M and L Trujillo. In press. Recent changes in sexual attitudes, norms, and behaviors among unmarried Thai men: a qualitative analysis. *International Family Planning Perspectives*.

VanLandingham M, J Knodel, Chanpen Saengtienchai, and Wassana Im-em. 2000. The impacts of HIV/AIDS on older populations in developing countries: Some observations based upon the Thai case. *Journal of Family Issues* 21(6):777-805.

VanLandingham. 2000. Unpublished field notes of interviews with local and provincial level health care personnel.

Weniger B, Khanchit Limpakarnjanarat, Kumnuan Ungchusak, Sombat Thanprasertsuk, Kachit Choopanya, Suphak Vanichseni, Thongchai Uneklabh, Prasert Thongcharoen, and Chantapong Wasi. 1991. The epidemiology of HIV infection and AIDS in Thailand. *AIDS* 5:S71-S85.

WorldBank (2000). Thailand's response to AIDS: building on success, confronting the future, World Bank.

**Table 1: Background characteristics of PWAs**

Background characteristics	Total			Province and sex of respondents											
	Total	Male	Female	Chiang Mai			Chiang Rai			Bangkok			Lampang		
				Male	Female	Total	Male	Female	Total	Male	Female	Total	Male	Female	Total
Sample size ( n )	424	139	285	29	71	100	31	69	100	49	51	100	30	94	124
(%)	100	33	67	29	71	100	31	69	100	49	51	100	24	76	100
Median age (years)	31	32	30	30	33	33	34	29	30	31	27	29	33	32	32
Occupation (%):															
-non ag laborer	41	35	43	41	54	50	42	51	48	8	0	4	67	53	56
-farmer	15	16	15	21	10	13	35	20	25	2	4	3	13	21	19
Rural background (%)	76	68	80	72	83	80	94	88	90	40	47	43	83	88	87
Current rural res (%)	65	56	69	68	80	78	97	83	87	8	4	6	80	86	85
Education level (%)															
-6 yr elem (P6) or less	73	64	78	55	82	74	87	88	88	45	57	51	80	78	78
Marital status (%)															
-single	13	34	2	28	1	9	19	0	6	55	12	33	20	0	5
-married	29	40	24	55	23	32	35	20	25	16	27	22	67	27	36
-divorced	4	8	3	3	3	3	13	3	6	8	6	7	7	1	2
-separated	8	9	8	3	4	4	13	7	9	12	25	19	3	3	3
-widowed	45	10	62	10	69	52	19	70	54	8	29	19	3	69	53
Has children (% yes)	63	38	75	52	85	75	32	70	58	20	65	43	60	79	74
Average number of living children (n) / those with children	1.4	1.6	1.3	1.3	1.3	1.3	2.4	1.3	1.5	1.7	1.3	1.4	1.4	1.4	1.4
For ever married respondents (n)	369	91	278	21	70	91	25	69	94	21	45	66	24	94	118
Spouse infected (% yes)	89	85	91	95	89	90	88	94	93	57	87	77	96	92	92
Lives with at least 1 parent (% yes)	17	21	16	7	8	8	23	19	20	18	6	12	37	24	27

**Table 2: Health and HIV related symptoms of PWAs**

Health variables	Total			Province and sex of respondents												
	Total	Total		Chiang Mai			Chiang Rai			Bangkok			Lampang			
		Male	Female	Male	Female	Total	Male	Female	Total	Male	Female	Total	Male	Female	Total	
Acknowledge HIV+ (%)	98	99	98	100	100	100	100	100	100	100	98	98	98	97	95	95
Current health status (% excellent or good)	28	24	29	14	30	25	26	35	32	31	33	32	20	23	23	
Ever had HIV related symptoms (%)	90	96	87	97	92	93	97	81	86	100	90	95	90	86	87	
Currently have HIV related health problems /ever any symptoms (%)	95	95	95	100	92	95	87	93	91	96	98	97	96	96	96	
Duration of symptoms (% in each category) /ever any symptoms																
? <6 mo	14	17	13	18	6	10	30	16	21	18	24	21	0	9	7	
? >= 6 mo < 1 yr	18	17	18	14	18	17	13	21	18	18	20	19	22	14	16	
? >= 1 yr < 3 yr	37	38	37	43	34	37	40	41	41	29	26	27	48	42	44	
? >= 3 yr	31	28	33	25	42	37	17	21	20	35	30	33	30	35	33	
Ever had HIV related fever /ever any symptoms	65	71	63	71	60	63	67	68	67	80	78	79	59	52	54	
-Headache	60	58	60	50	54	53	63	64	64	67	65	66	44	60	57	
-Weight loss	54	66	48	64	40	47	67	48	55	71	67	70	56	42	45	
-Digestive problems	35	50	27	64	25	37	50	38	42	49	37	43	37	15	20	
-Respiratory problems	39	47	34	39	22	27	57	52	54	49	30	40	41	35	36	
-Skin and mouth rashes	51	55	49	64	52	56	63	52	56	53	52	53	41	43	43	
-Tiredness and/or exhaustion	53	60	50	64	42	48	40	55	50	78	83	80	44	35	37	
-Difficulty moving about	11	16	8	21	0	7	17	14	15	14	17	16	15	6	8	
-Unable to work	16	27	10	21	2	8	37	23	28	20	15	18	33	6	13	
-Unable to leave house alone	5	8	4	11	0	3	10	9	9	2	4	3	15	4	7	
-Unable to dress myself	2	4	1	0	0	0	10	0	4	2	4	3	4	0	1	
-Unable to walk	3	7	1	7	0	2	13	2	6	4	4	4	4	0	1	
-Other symptoms	10	11	9	7	8	8	17	7	11	10	11	11	11	11	11	

**Table 3: Types of treatments PWAs report receiving**

Types of treatments	Total						Province and education level of respondents															
	Total	Sex		Education Level			Chiang Mai				Chiang Rai				Bangkok				Lampang			
		Male	Female	Low	Med	High	Low ed	Med ed	Hi ed	Total	Low ed	Med ed	Hi ed	Total	Low ed	Med ed	Hi ed	Total	Low ed	Med ed	Hi ed	Total
Ever received treatment for HIV/AIDS and/or symptoms(%)	84	91	80	83	82	86	87	79	96	87	74	87	92	82	93	74	78	81	83	82	89	84
Ever received modern treatment (%)	71	82	66	72	68	75	76	66	85	75	53	69	50	60	89	65	71	75	75	70	85	75
-mentioned antiretrovirals (%)	7	6	7	5	8	8																
-mentioned TB treatment or prophylaxis (%)	7	6	8	10	8	3																
-mentioned other antibiotics or OI treatment (%)	9	9	9	8	7	12																
-received treatment for pain or symptoms (%)	6	5	7	8	6	5																
Ever received herbal treatment (%)	30	29	31	31	36	22				35				62				15				14
-mentioned bitter cucumber (%)	12	8	14	12	14	8																
-mentioned green chiretta (%)	9	6	11	11	12	4																
Ever received meditative treatment (%)	13	11	14	12	15	13				30				11				10				4

Note: Low education = less than 6 yrs; medium = 6 yrs; high = more than 6 yrs.

**Table 4: Costs and sources of payments for treatments for PWAs**

Costs and sources of payments	Total						Province and education level of respondents																
	Sex			Education Level			Chiang Mai				Chiang Rai				Bangkok				Lampang				
	Total	Male	Female	Low	Med	High	Low ed	Med ed	Hi ed	Total	Low ed	Med ed	Hi ed	Total	Low ed	Med ed	Hi ed	Total	Low ed	Med ed	Hi ed	Total	
Total amount spent on treatment (mode) /any																							
< 1000 baht	34	30	35	32	38	31	31	35	20	29	31	28	36	30	16	6	26	19	45	57	46	51	
1000 – 4999 baht	30	32	29	33	30	28	38	43	44	41	34	21	18	26	40	63	26	38	18	19	17	18	
5000 – 9999 baht	12	10	13	9	15	12	10	13	8	10	9	23	18	17	4	25	18	15	9	6	4	7	
10,000 – 19,999 baht	8	7	8	10	5	8	8	0	4	5	16	8	9	11	12	0	8	8	6	6	13	8	
20,000 – 49,000 baht	8	11	7	9	6	11	5	9	8	7	9	8	18	10	20	6	13	14	3	2	8	4	
>= 50,000 baht	5	8	4	5	5	7	8	0	16	8	0	13	0	6	8	0	5	5	3	2	4	3	
DK	3	1	4	4	2	3	0	0	0	0	0	0	0	0	0	0	3	1	15	6	8	10	
Total	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100	
Percent having a gov't hith card/ever rec treatment	62	46	71	66	74	43	74	78	44	67	81	69	82	76	15	24	8	14	82	94	79	87	
Primary source of medical payment /any (percent):																							
Yourself	34	31	35	37	28	37	55	55	44	52	31	23	27	27	50	60	41	48	7	7	27	12	
Your spouse	6	11	4	7	5	8	3	4	8	5	6	5	0	5	0	7	6	4	18	5	14	11	
Other family	5	9	3	9	1	7	8	0	4	5	6	3	0	4	25	0	15	15	0	0	0	0	
Your mother	8	9	7	2	9	12	3	14	12	8	3	18	9	11	0	7	12	7	4	0	14	4	
Your father	2	4	1	2	2	3	5	0	4	4	0	5	9	4	4	0	3	3	0	0	0	0	
Friends	0	0	0	0	1	0	0	0	0	0	0	3	0	1	0	0	0	0	0	0	0	0	
Government health card insurance system	32	20	38	32	42	18	16	14	12	14	53	41	55	48	4	0	3	3	54	73	32	57	
Government health care system for civil servants	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	2	0	1	
Government social security system	7	8	6	6	9	7	8	14	16	12	0	3	0	1	4	7	0	3	11	12	9	11	
Government social welfare	1	2	0	2	0	0	3	0	0	1	0	0	0	0	8	0	0	3	0	0	0	0	
Health insurance offered by workplace	1	0	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	3	0	5	2	
Other	4	5	3	2	3	8	0	0	0	0	0	0	0	0	4	20	21	15	3	0	0	1	
Total	100	100	100	100	101	100	101	101	100	101	99	101	100	101	99	101	101	101	100	99	101	99	

Notes: Low education = less than 6 yrs; medium = 6 yrs; high = more than 6 yrs.  
Some totals may not equal 100% due to rounding.

Table 5: Care taking of PWAs having AIDS-related symptoms

Care taking variables	Total							Marital status, symptom duration, and sex of respondents											
	Total	Marital Status		Symptom Duration		Sex		Not Currently Married				Currently Married							
		Not currently married	Married	< 1 year	≥ 1 year	Male	Female	< 1 year duration		≥ 1 year duration		< 1 year duration		≥ 1 year duration					
								Male	Female	Male	Female	Male	Female	Male	Female				
<i>Current major caretaker (%)</i>																			
-yourself	40	46	24	33	43	44	38	43	31	63	46	33	26	18	23				
-your spouse	16	-----	55	14	16	22	12	-----	-----	-----	-----	39	43	67	60				
-other family	13	17	5	10	15	7	17	7	14	12	22	0	13	3	3				
-your mother	20	23	13	28	17	17	22	32	35	12	22	22	13	9	10				
-your father	2	3	0	2	3	2	3	0	4	4	4	0	0	0	0				
-friends	2	2	1	2	2	2	2	4	2	4	2	0	0	0	3				
-health care professional	3	3	2	4	2	4	3	4	6	4	2	6	0	0	0				
-other	3	4	1	7	2	3	3	11	8	2	2	0	4	3	0				
Total percents	100	100	100	100	100	100	100	100	100	100	100	100	100	100	100				
N	364	260	104	118	246	131	233	28	49	52	131	18	23	33	30				
<i>Anticipated major caretaker if became very ill (%)</i>																			
-your spouse	18	0.4*	60	16	19	28	13				0.8*	53	38	82	59				
-other family	30	39	9	20	35	19	36	26	26	33	48	0	17	0	19				
-your mother	31	35	24	41	27	27	34	41	46	25	33	41	33	12	19				
-your father	5	6	2	5	4	2	6	0	9	4	7	6	4	0	0				
-friends	6	7	3	6	5	9	3	19	4	10	4	0	0	6	3				
-other	10	14	2	11	10	15	8	15	15	29	7	0	8	0	0				
Total percents	100	100	100	100	100	100	100	100	100	100	99	100	100	100	100				
N	360	254	106	114	246	129	231	27	46	52	129	17	24	33	32				

Note: \* 1 case of a separated female.

**Table 6: Migration of PWAs**

Migration variables	Total						Province, sex, and education level of respondents											
	Total	Sex		Education level			Bangkok					Provincial						
		Male	Female	Low ses	Med ses	Hi ses	Sex		Education level			Total	Sex		Education level			Total
							Male	Female	Low ed	Med ed	Hi ed		Male	Female	Low ed	Med ed	Hi ed	
Q45 Non permanent residents in current household (Q45) %	59	62	58	52	60	69	80	90	86	87	84	85	52	51	44	55	58	51
Q46 Moved to current residence because of illness? (% yes/non perm res).	39	43	37	43	39	35	62	46	67	50	46	53	28	34	32	36	24	32
N responding yes to Q46	98	37	61	34	36	28	24	21	16	10	19	45	13	40	18	26	9	53
Q47 Main reasons for move*:																		
- Need more financial support	27	22	30	26	36	14	insufficient cell sizes					24	insufficient cell sizes					28
- Need help taking care of myself	71	70	72	82	72	57						58						83
- Need help taking care of my children	24	11	33	26	31	14						13						34
- Lonely	18	14	21	21	17	18						20						17
- Disaffected or bored	17	27	11	15	11	29						27						9
- Other	20	24	18	15	25	21	22	19										
Q49 Would move if health got worse (% yes).	9	13	7	6	11	11	22	16	21	23	16	19	8	6	2	9	8	6

Notes: \* Multiple response: will not sum to 100%

Note: Low education = less than 6 yrs; medium = 6 yrs; high = more than 6 yrs.

**Table 7: Community Reaction to PWAs**

Community Reaction	Total	Province, sex, and ses of respondents								
		Sex		Education level			Province			
		Male	Female	Low ed	Med ed	Hi ed	CM	CR	Bkk	LP
Q56. Community reaction to PWAs generally*										
- No reaction; no different from before	21	20	21	23	19	18	21	32	8	21
- general talk	30	29	31	31	33	26	41	43	23	18
- sympathy	41	31	46	35	53	32	33	62	12	53
- support	49	34	56	46	62	35	41	73	12	65
- help the PWA	19	11	22	16	23	16	18	28	7	21
- disgust/fear	28	30	26	31	23	29	23	32	30	26
- look down upon	20	20	19	26	16	16	24	23	18	15
- gossip	39	37	40	47	35	33	47	45	35	31
Q57. Community knows about HIV status of R (%yes).	80	71	85	87	85	65	91	93	42	93
n responding yes for Q57	341	98	243	136	131	74	91	93	42	115
Q58. Community reaction to respondent/those whose community know (%) *										
- No reaction; no different from before	19	22	18	21	19	16	21	25	14	16
- general talk	32	36	30	29	35	31	41	41	40	14
- sympathy	51	39	56	43	63	45	35	61	24	65
- support	57	42	63	47	71	49	43	72	12	71
- help the PWA	23	15	26	18	29	23	16	32	17	23
- disgust/fear	33	43	29	35	26	42	30	35	60	24
- look down upon	24	30	22	32	18	20	29	25	38	15
- gossip	45	47	44	50	40	43	53	47	52	33

Notes: \* Multiple response: will not sum to 100%

Note: Low education = less than 6 yrs; medium = 6 yrs; high = more than 6 yrs.

Appendix: PHA questionnaire

**PWA Self-administered Questionnaire**

Location of interview: \_\_\_\_\_ Province  
\_\_\_\_\_ Amphur  
\_\_\_\_\_ Tambol  
\_\_\_\_\_ Date  
\_\_\_\_\_ Name of administrator/interviewer

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*Thank you for being willing to participate in our study. Our project's goal is to try to assess some of the major problems faced by PWAs and their families as they cope with the PWA's illness. At the end of each question or statement, we ask that you fill in the blank, or circle the number for the appropriate response(s) that best answer the issue for you.*

*Your participation is voluntary and the questionnaire is anonymous. We don't ask for your name anywhere on the form. If you feel uncomfortable about answering any of the questions, feel free to skip them. The administrator is here to help answer any questions you may have.*

1. How old are you? \_\_\_\_\_ years old
2. Please circle the correct category for sex:
  - 1 Male
  - 2 Female
3. Is there anyone living in your household who is 50 years old or older?
  - 1 Yes
  - 2 No
4. Is there anyone living in your household who is 60 years old or older?
  - 1 Yes
  - 2 No
5. What kind of area are you living in now? (*circle **only one** answer*)
  - 1 Rural village
  - 2 Sanitary district
  - 3 Provincial or district town
  - 4 Bangkok
6. In what kind of area did you grow up in? (*circle **only one** answer*)
  - 1 Rural village
  - 2 Sanitary district
  - 3 Provincial or district town
  - 4 Bangkok
7. What is the highest grade of education you have completed? \_\_\_\_\_ grade
8. What is your current or most recent occupation? \_\_\_\_\_

9. What is your marital status? (*circle **only one** answer*)
- 1 Never married (*skip to question 11*)
  - 2 Currently married or living together
  - 3 Divorced
  - 4 Separated
  - 5 Widowed
10. Are you now or have you ever been married to someone who suffered from AIDS or who was infected with the AIDS virus? (*circle **all that apply***)
- 1 Yes, my current spouse is infected
  - 2 Yes, my former spouse was infected but s/he died
  - 3 Yes, my former spouse is/was infected but we separated or divorced.
  - 4 I suspect that my current spouse is infected.
  - 5 I suspect that a former spouse was infected.
  - 6 No
11. Do you have children?
- 1 Yes
  - 2 No (*skip to question 16*).
12. How many children do you have? \_\_\_\_\_ children
13. How old is the oldest child? \_\_\_\_\_ years old
14. (*If you have more than one child:* ) How old is the youngest child? \_\_\_\_\_ years old
15. Who all plays a major role in the care of your children? (*circle **all that apply***)
- 1 They care for themselves.
  - 2 Myself
  - 3 Spouse
  - 4 My mother
  - 5 My father
  - 6 My mother in law
  - 7 My father in law
  - 8 My brother(s)
  - 9 My sister(s)
  - 10 My grandmother
  - 11 My grandfather
  - 12 Other male relatives
  - 13 Other female relatives
  - 14 Male friends
  - 15 Female friends
  - 16 Other (specify): \_\_\_\_\_
16. Is your mother still alive?
- 1 Yes
  - 2 No (*skip to question 21*)
  - 3 Don't know (*skip to question 21*).
17. If yes, how old is she? \_\_\_\_\_ years old

18. How is her health (*circle only one answer*)?
- 1 Excellent
  - 2 Good
  - 3 Fair
  - 4 Poor
19. Is your mother healthy enough to be able to take care of you if you should become very ill? (*circle only one answer*)
- 1 Yes
  - 2 No
  - 3 Don't know
20. Where does your mother live now? (*circle only one answer*)
- 1 In the same house with me
  - 2 In the same compound or in an adjoining house ("ban thik gan; krabkrua deo-gan")
  - 3 In the same proximate area ("nai ket deo-gan")
  - 4 Somewhere else
21. Is your father still alive?
- 1 Yes
  - 2 No (*skip to question 26*)
  - 3 Don't know (*skip to question 26*).
22. If yes, how old is he? \_\_\_\_\_ years old
23. How is his health? (*circle only one answer*)
- 1 Excellent
  - 2 Good
  - 3 Fair
  - 4 Poor
24. Is your father healthy enough to be able to take care of you if you should become very ill? (*circle only one answer*)
- 1 Yes
  - 2 No
  - 3 Don't know
25. Where does your father live now? (*circle only one answer*)
- 1 In the same house with me
  - 2 In the same compound or in an adjoining house ("ban thik gan; krabkrua deo-gan")
  - 3 In the same proximate area ("nai ket deo-gan")
  - 4 Somewhere else
26. To verify information about your parents, please circle the correct choice below (*circle only one answer*):
- 1 Both your mother and father are alive (*go to question 27*).
  - 2 Only your mother is alive; your father is not alive (*skip to question 28*).
  - 3 Only your father is alive; your mother is not alive (*skip to question 28*).
  - 4 Neither your father nor your mother are alive (*skip to question 28*).
27. Are your parents living together now?
- 1 Yes
  - 2 No
  - 3 Don't know

28. Do you think that you are infected with HIV ? (*circle **only one** answer*)
- 1 Yes - I tested positive.
  - 2 Yes - I think that I am positive, but I haven't been tested.
  - 3 Yes - Although I tested negative, I still think that I am infected.
  - 4 No - I tested negative (*skip to question 30*).
  - 5 No - I think I am negative, but I haven't been tested (*skip to question 30*).
29. How long have you known or suspected that you are HIV positive? (*circle **only one** answer*)
- 1 Less than 6 months
  - 2 6 months or more but less than 1 year
  - 3 1 year or more but less than 3 years
  - 4 More than 3 years
30. How is your health now? (*circle **only one** answer*)
- 1 Excellent
  - 2 Good
  - 3 Fair
  - 4 Poor
31. Have you **ever** had any symptoms that you think might be related to the AIDS virus? (*circle **only one**: yes or no*)
- 1 No (*skip to question 34*).
  - 2 Yes - What are the symptoms? (*circle **all** the symptoms below that apply*)
- 1 Fever
  - 2 Headache
  - 3 Weight loss
  - 4 Digestive problems, e.g., diarrhea
  - 5 Respiratory problems, e.g., coughing
  - 6 Skin and mouth rashes
  - 7 Tiredness and/or exhaustion
  - 8 Difficulty moving about
  - 9 Unable to work
  - 10 Unable to leave the house alone
  - 11 Unable to dress myself
  - 12 Unable to walk
  - 13 Other (*please specify*):
- 
32. Beginning from when you **first** began to have symptoms, how long would you say that you have had symptoms that might be related to the AIDS virus? (*circle **only one***)
- 1 Less than 6 months
  - 2 6 months or more but less than 1 year
  - 3 1 year or more but less than 3 years
  - 4 More than 3 years
33. Do you **currently** have any health problems related to HIV? (*circle **only one**: no or yes*)
- 1 No (*go to question 34*).
  - 2 Yes - What are the symptoms (*circle **all** symptoms below that apply*)
- 1 Fever
  - 2 Headache
  - 3 Weight loss
  - 4 Digestive problems, e.g., diarrhea
  - 5 Respiratory problems, e.g., coughing

- 6 Skin and mouth rashes
  - 7 Tiredness and/or exhaustion
  - 8 Difficulty moving about
  - 9 Unable to work
  - 10 Unable to leave the house alone
  - 11 Unable to dress myself
  - 12 Unable to walk
  - 13 Other (*please specify*):
- 

34. Have you ever received any treatment to combat the AIDS virus or AIDS-related symptoms? (*circle either no or yes*)

- 1 No (*skip to question 40*).
- 2 Yes - What types of treatments? (*circle all the treatments below that apply*)

1 Modern medicines (*specify what types if known*): \_\_\_\_\_

\_\_\_\_\_

2 Herbal medicines (*specify what types if known*): \_\_\_\_\_

\_\_\_\_\_

3 Mediation

4 Other treatments (*specify*): \_\_\_\_\_

35. Do you currently have a government issued health card?

- 1 Yes
- 2 No
- 3 Don't know

36. Do you currently have a welfare card?

- 1 Yes
- 2 No
- 3 Don't know

37. What do you estimate has been the **total** amount that you and your family have paid for on your own (not reimbursed) on all expenses associated with your AIDS illness? Please include costs of medicine and other treatments, plus costs for transportation, housing and food for yourself and accompanying relatives when you have had to go away for treatment. (*circle only one category*).

- 1 Less than 1000 baht
- 2 Between 1000 and 4999 baht
- 3 Between 5000 and 9999 baht
- 4 Between 10,000 and 19,999 baht
- 5 Between 20,000 and 49,999 baht
- 6 50,000 baht or more (*specify total amount if known*: \_\_\_\_\_ baht)

38. Who all helped pay for the treatments? (*circle all that apply*)

- 1 Paid for treatment yourself
- 2 Your spouse
- 3 Your son(s)
- 4 Your daughter(s)
- 5 Your mother
- 6 Your father
- 7 Your brother(s)
- 8 Your sister(s)
- 9 Your father in law
- 10 Your mother in law
- 11 Your grandmother
- 12 Your grandfather
- 13 Other male relatives
- 14 Other female relatives
- 15 Male friends
- 16 Female friends
- 17 Government health card insurance system
- 18 Government health care system for civil servants
- 19 Government social security system
- 20 Government social welfare system
- 21 Private insurance
- 22 Health insurance offered by my workplace
  
- 23 Other (*specify*): \_\_\_\_\_

39. Who was the primary source of payment for the treatments? (*circle only one answer*)

- 1 Paid for treatment mostly yourself
- 2 Your spouse
- 3 Your son(s)
- 4 Your daughter(s)
- 5 Your mother
- 6 Your father
- 7 Your brother(s)
- 8 Your sister(s)
- 9 Your father in law
- 10 Your mother in law
- 11 Your grandmother
- 12 Your grandfather
- 13 Other male relatives
- 14 Other female relatives
- 15 Male friends
- 16 Female friends
- 17 Government health card insurance system
- 18 Government health care system for civil servants
- 19 Government social security system
- 20 Government social welfare system
- 21 Private insurance
- 22 Health insurance offered by my workplace
  
- 23 Other (*specify*): \_\_\_\_\_

40. Who all takes care of you physically (“do lae piyaban”) now when you are sick? (*circle all that apply*)

- 1 Yourself
- 2 Your spouse
- 3 Your son(s)
- 4 Your daughter(s)
- 5 Your mother
- 6 Your father
- 7 Your brother(s)
- 8 Your sister(s)
- 9 Your father in law
- 10 Your mother in law
- 11 Your grandmother
- 12 Your grandfather
- 13 Other male relatives
- 14 Other female relatives
- 15 Male friends
- 16 Female friends
- 17 A health care professional, e.g. a nurse
  
- 18 Other (*specify*): \_\_\_\_\_

41. Who is the **main** person taking care of you now physically (“do lae piyaban”) when you are sick? (*circle only one answer*)

- 1 Yourself
- 2 Your spouse
- 3 Your son(s)
- 4 Your daughter(s)
- 5 Your mother
- 6 Your father
- 7 Your brother(s)
- 8 Your sister(s)
- 9 Your father in law
- 10 Your mother in law
- 11 Your grandmother
- 12 Your grandfather
- 13 Other male relatives
- 14 Other female relatives
- 15 Male friends
- 16 Female friends
- 17 A health care professional, e.g. a nurse
- 18 Other (*specify*): \_\_\_\_\_

42. Who all are you currently living with now, in the same house or compound (“ban thik gan; krabkrua deo-gan”) ? (*circle all that apply*)

- 1 Your spouse
- 2 Your son(s)
- 3 Your daughter(s)
- 4 Your mother
- 5 Your father
- 6 Your brother(s)
- 7 Your sister(s)
- 8 Your father in law
- 9 Your mother in law
- 10 Your grandmother
- 11 Your grandfather

- 12 Other male relatives
- 13 Other female relatives
- 14 Male friends
- 15 Female friends
- 16 Other (*specify*): \_\_\_\_\_

43. Who all helps support you financially now? (*circle all that apply*)

- 1 Yourself
- 2 Your spouse
- 3 Your son(s)
- 4 Your daughter(s)
- 5 Your mother
- 6 Your father
- 7 Your brother(s)
- 8 Your sister(s)
- 9 Your father in law
- 10 Your mother in law
- 11 Your grandmother
- 12 Your grandfather
- 13 Other male relatives
- 14 Other female relatives
- 15 Male friends
- 16 Female friends
- 17 Funds from the government Social Welfare Office
- 18 Other (*specify*): \_\_\_\_\_

44. Who is the **main** person or source supporting you financially now? (*circle only one answer*)

- 1 Yourself
- 2 Your spouse
- 3 Your son(s)
- 4 Your daughter(s)
- 5 Your mother
- 6 Your father
- 7 Your brother(s)
- 8 Your sister(s)
- 9 Your father in law
- 10 Your mother in law
- 11 Your grandmother
- 12 Your grandfather
- 13 Other male relatives
- 14 Other female relatives
- 15 Male friends
- 16 Female friends
- 17 Funds from the government Social Welfare Office
- 18 Other (*specify*): \_\_\_\_\_

45. How long have you been living in the house or compound (“ban thik gan; krabkrua deo-gan”) where you are now? (*circle only one answer*)

- 1 Less than 6 months
- 2 6 months or more but less than a year
- 3 1 year or more but less than 5 years
- 4 5 years or more
- 5 Always; I have never moved (*skip to question 49*).

46. Did you move here because of your HIV condition?

- 1 Yes
- 2 No (*skip to question 48*)

47. What were the main reasons for moving here? (*circle all that apply*)

- 1 Need more financial support
- 2 Need help taking care of myself
- 3 Need help taking care of my children
- 4 Lonely
- 5 Boredom
- 6 Other (*explain*): \_\_\_\_\_

48. How many times did you move (“yai ti yu”) during the past year? \_\_\_\_\_ times

49. If your health got worse, do you think that you would move in with others? (*circle only one answer*)

- 1 Yes (*go on to question 50*)
- 2 No (*skip to question 52*)
- 3 Don't know (*skip to question 52*).

50. If yes, why do you think you might move in with others? (*circle all that apply*)

- 1 Need more financial support
- 2 Need help taking care of myself
- 3 Need help taking care of my children
- 4 Lonely
- 5 Boredom
- 6 Other (*explain*): \_\_\_\_\_

\_\_\_\_\_

51. Who all might you move in with? (*circle all that apply*)

- 1 Your spouse
- 2 Your son(s)
- 3 Your daughter(s)
- 4 Your mother
- 5 Your father
- 6 Your brother(s)
- 7 Your sister(s)
- 8 Your father in law
- 9 Your mother in law
- 10 Your grandmother
- 11 Your grandfather
- 12 Other male relatives
- 13 Other female relatives
- 14 Male friends
- 15 Female friends
- 16 Other (*specify*): \_\_\_\_\_

52. If your health got worse, do you think others would come move in with you? (*circle only one answer*)

- 1 Yes
- 2 No (*skip to question 55*).
- 3 Don't know (*skip to question 55*).

53. If yes, why do you think they might move in? (*circle all that apply*)

- 1 To give financial support
  - 2 To help me take care of myself
  - 3 To help me take care of my children
  - 4 Other (*explain*):
- 
- 

54. Who all might move in with you? (*circle all that apply*)

- 1 Your spouse
  - 2 Your son(s)
  - 3 Your daughter(s)
  - 4 Your mother
  - 5 Your father
  - 6 Your brother(s)
  - 7 Your sister(s)
  - 8 Your father in law
  - 9 Your mother in law
  - 10 Your grandmother
  - 11 Your grandfather
  - 12 Other male relatives
  - 13 Other female relatives
  - 14 Male friends
  - 15 Female friends
  - 16 Other (*specify*):
- 

55. Who do you think would be your **main** caretaker if you became very ill (*circle only one answer*)?

- 1 Your spouse
  - 2 Your son(s)
  - 3 Your daughter(s)
  - 4 Your mother
  - 5 Your father
  - 6 Your brother(s)
  - 7 Your sister(s)
  - 8 Your father in law
  - 9 Your mother in law
  - 10 Your grandmother
  - 11 Your grandfather
  - 12 Other male relatives
  - 13 Other female relatives
  - 14 Male friends
  - 15 Female friends
  - 16 Other (*specify*):
- 

56. In the community where you live now, what are the general reactions to people who are known or suspected to be PWAs? (*circle all that apply*)

- 1 No reaction; no different from before
- 2 General talk (“poot taw taw gan”)
- 3 Sympathy (“hen jai”)
- 4 Support (“hai gomlang jai”)
- 5 Help the PWA (“chuay gan”)
- 6 Disgust/fear (“rang giet”)
- 7 Look down upon (“do toog”)

- 8 Gossip (“wijan”)
  - 9 Don’t know or no opinion
  - 10 Other (specify):
- 
- 

57. Do people in the community where you live now know or suspect that you are a PWA?

- 1 Don’t know - *(please skip to the end of the questionnaire)*
- 2 No - *(please skip to the end of the questionnaire)*
- 3 Yes - *(please go on to question 58)*

58. How do most people in your community who know or suspect that you are a PWA react to you? *(circle all that apply)*

- 1 No reaction; no different from before
  - 2 General talk (“poot taw taw gan”)
  - 3 Sympathy (“hen jai”)
  - 4 Support (“hai gomlang jai”)
  - 5 Help the PWA (“chuay gan”)
  - 6 Disgust/fear (“rang giet”)
  - 7 Look down upon (“do toog”)
  - 8 Gossip (“wijan”)
  - 9 Don’t know or no opinion
  - 10 Other (specify):
- 
- 

*Administrator: Please allow the informant to talk about the last issue (community reaction) or any other topics covered in the questionnaire if they wish to do so (don’t press them to). Otherwise, change the subject to an easy general topic, and wind down the interview. Be sure to thank the respondent for their time.*