



THE IMPACT OF THAILAND'S AIDS EPIDEMIC ON OLDER PERSONS:

QUANTITATIVE EVIDENCE FROM
A SURVEY OF KEY INFORMANTS

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PREFACE

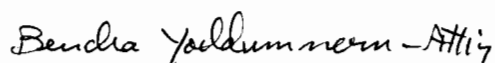
This is the first of a planned series of reports to come from the project "Impact of the HIV/AIDS Epidemic upon the Older Population in Thailand, funded by the National Institute on Aging, the U.S. National Institutes of Health (Grant AG15983). The project is a collaborative one between the Population Studies Center, University of Michigan, the Department of International Health and Development, Tulane University, and the Institute for Population and Social Research, Mahidol University. The principal investigators are Wassana Im-em, John Knodel, Chanpen Saengtienchai and Mark VanLandingham. The overall project goal is to assess systematically how and to what extent the older population (age 50 and above) is being affected by the HIV/AIDS epidemic in Thailand. More specifically, the project seeks to determine the number and proportion of older persons who will suffer the death of an adult child to AIDS before their own deaths; the frequency, type, and severity of the consequences experienced by older persons who do experience this event; and the knowledge, attitudes and practices (KAP) of older persons related to AIDS, including care-giving practices.

We pursue these aims using a variety of data collection and analytical techniques. These include a key informant survey, a KAP survey, a self-administered survey of persons with AIDS, extraction of data from AIDS related welfare applications, a direct interview impact survey, open-ended interviews, analysis of existing survey data regarding older persons, the use of standard demographic analysis techniques and microsimulation. The present report is based on the key informant survey. Future reports in this series will present the results from other key project components.

FOREWARD

The AIDS situation in Thailand is still at the alarming stage with about one million people projected to be those living with HIV and over 200,000 people had died with AIDS. Although Thailand has been recognized worldwide as a success story in dealing with the epidemic effectively, the impact of AIDS on the population is still a major concern by related organizations and by people living with AIDS and their families. What has never been studied in details before is the situation of the elderly people who are affected by the AIDS epidemic or the elderly people who are infected with HIV. Little is known about the elderly people's well being after their children are infected and dying with AIDS.

This study on the impact of AIDS on the elderly is an important pioneer work. It is a collaborative research of the Institute for Population and Social Research, Mahidol University, Population Studies Center, University of Michigan, and Department of International Health and Development, School of Public Health and Tropical Medicine, Tulane University. Prof. John Knodel's and Ms. Chanpen Saengtienchai's strong research background on the elderly people in Thailand and Dr. Wassana Im-em's and Dr. Mark VanLandingham's research experiences in sexual behavior and HIV/AIDS gave the strength of this research team. We hope that this study will provide points for discussion that will allow policy makers, NGOs and academics to produce policy and strategies to help the elderly people in dealing with AIDS.



**Bencha Yoddumnern-Attig, Director
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This study would have been a difficult task, had we not received assistance and co-operation from various organizations and persons.

We realize that the data collection for our research project took the valuable time of many people. We would like to express our appreciation to the public health staff at provincial public health offices and health stations in Chiang Mai, Chiang Rai, Rayong, Petchburi, Khon Kaen, Ubonratchathani, Phuket, Phichit, and Bangkok for their effective co-ordination of this research project. We are grateful to public health station staff and village health volunteers from these provinces who kindly discussed with us in lengthy time to give details about people living with AIDS in the area of their responsibility.

We thank HelpAge who gave us valuable information about their work on the elderly people affected by AIDS in Chiang Mai. ACCESS gave us useful information about the situation of people living with AIDS in Bangkok. The Social Welfare Division for people living with AIDS in Chiang Mai, Rayong, and Khon Kaen kindly provided us with useful information obtained from the applications for AIDS welfare.

We would like to thank Kullawee Siriratmongkon, the project secretary, for her effective co-ordination and tireless contribution throughout this project.

ABSTRACT

Discussions of the AIDS epidemic rarely consider the impact on older persons and when they do, focus is typically on those who are infected themselves. Virtually no systematic quantitative assessments exist of the involvement of parents or other older generation relatives in the living and caretaking arrangements of persons with AIDS in either the West or the developing world. We assess the extent of such types of involvement in Thailand and examine the parental characteristics associated with them. We also examine the economic impact on the families and parents through expenditures on treatments and a number of other routes. Interviews with local key informants in the public health system in an extensive sample of rural and urban communities provided quantitative information on a total of 963 adult cases who either had died of AIDS or were currently symptomatic.

The results indicate that a substantial proportion of persons with AIDS move back to their communities of origin at some stage of the illness. Two-thirds of the adults who died of AIDS either lived with or adjacent to a parent by the terminal stage of illness and a parent, usually the mother, acted as a main caregiver for about half. For 70 percent, either a parent or other older generation relative provided at least some care. The vast majority of the parents were age 50 or more and many were age 60 or older. The economic impacts appear to be severe for only a minority of parents although those who are from the poorer economic strata are particularly likely to be substantially affected adversely. The wide availability of government health insurance likely moderates the economic impact on families.

A substantial majority of families in the upper north are reported to be open to the community about a family member being ill with AIDS but only about half of families outside the upper north were considered to be open. Negative community reactions during the time of illness to families with a member who had AIDS was reported for a fifth of the families in the upper North and a third elsewhere. Following the death, few cases of residual negative reaction were reported anywhere.

This extent of older generation involvement in living and caregiving arrangements appears to be far greater in Thailand than in Western countries such as the US. We interpret the difference as reflecting the contrasting epidemiological and socio-cultural situations in Thailand and the West. The fact that older people in Thailand, and probably many other developing countries, are extensively impacted by the AIDS epidemic through their involvement with their infected adult children has important implications for public health programs that address caretaker education and social and economic support.

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Introduction

HIV/AIDS is usually viewed as a disease affecting reproductive age adults and their infant children. Discussions rarely consider the impact on older persons and when they do, they typically focus on those who are infected themselves (e.g. Nokes, 1996; Riley et al. 1989; Ory et al. 1998a). A far greater number of older persons, however, are affected through the infection of significant others, especially as parents of persons with AIDS (Allers 1990; Brabant 1994; Levine-Perkell 1996; Ory and Mack, 1998). AIDS can impact parents through numerous routes including 1) strains of care-giving and associated opportunity costs 2) providing financial and material support 3) raising surviving grand children 4) suffering emotional stress and 5) losing old-age support that the child would have provided (VanLandingham et al. 2000). The impact of AIDS compared to other diseases can be particularly severe given the lengthy periods of illness and disability, the untimely nature of the death, and possible negative community reactions to persons with AIDS and their families (Mullan 1998; Brown and Sankar 1998; Ellis and Muschkin 1996). Yet few studies focus on older people as parents of persons with AIDS (see however Brabant 1994; Ellis and Muschkin 1996; Levine-Perkell 1996; Mullan 1998; Nazon and Levine-Perkell 1996; Sankar et al., 1998). Even rarer are quantitative assessments of how frequently this dimension of the epidemic impacts the older population.

The limited literature on AIDS and older persons relates mainly to the United States or other developed countries. The applicability of this literature based on the U.S. to other settings is constrained by the fact that these studies frequently focus on the special problems and circumstances of AIDS caregiving within the gay community. Moreover those few existing studies rarely provide quantitative assessments (see, however, Crystal and Schiller 1993; LeBlanc et al. 1997; Mullan 1998; Turner and Catania 1997; Turner et al. 1994 and 1998). Perspectives from other settings are necessary to understand the fuller range of societal responses to the epidemic and how they are conditioned by the combination of culture, political system, and levels of social and economic development (Ory et al. 1998b; Sankar et al. 1998; Spira et al. 1998). More importantly, consequences for the older generation are likely to be even more common and pronounced in developing countries where HIV prevalence is often much higher than in the U.S. and where dependence on intergenerational arrangements for caregiving and support is more pervasive.

The present study uses a key informant approach to assess the extent of the impact of the AIDS epidemic on older persons in Thailand through the illness and death of their adult children or other younger generation relatives. Thailand is particularly well suited for such a study in a developing country context. The Thai AIDS epidemic is the most advanced in Asia (UNAIDS/WHO 1998; MAP 1998) and sufficiently far along for repercussions to be manifest and thus suitable for systematic investigation. Moreover, good quality epidemiological data on AIDS and extensive research into the general situation of the older population are available to provide important background information (e.g. Brown et al., 1994; Knodel et al., forthcoming-a; UNAIDS 1998a and b).

The Thai Setting

Recent estimates indicate almost 800,000 Thais had been infected by HIV by the end of 1997 and 260,000 had already died of AIDS, with 60,000 dying in 1997 alone (UNAIDS 1998a). Although incidence has fallen in response to aggressive organized efforts to combat the epidemic (Phoolcharoen et al. 1998; UNAIDS 1998b), UN and Thai government projections both indicate that deaths will increase for some years to come (NESDB 1994; UN 1999). In several upper northern provinces where the epidemic has been the worst, the overall death rate more than doubled between 1990 and 1996 as a result of tens of thousands of excess deaths, presumably attributable to AIDS (Im-Em 1999; van Griensven et al. 1998).

In common with most developing countries, heterosexual intercourse is the overwhelming route of HIV transmission in Thailand (over 90 percent of cases reported through 1999). Intravenous drug use accounts for 5 percent and homosexual/bisexual relations for 1 percent. Much of the epidemic has been driven by commercial sex patronage although infected men are increasingly spreading the virus to their wives and non-commercial partners (Brown and Sittitrai 1995; Brown and Xenos 1994; Ford and Koetsawang 1991).

Intergenerational exchanges of services and material support remain pervasive in Thailand as they do in much of the developing world (World Bank 1994). Widespread norms support filial obligations to parents, including expectations of old age support in the form of remittances and coresidence (Knodel et al. 1995). As recently as 1995, nearly three-quarters of parents aged 60 or above coresided with an adult child and 90 percent either lived with or had daily contact with one. Among persons aged 60 or over with children living outside the household, 89 percent received food or clothes from them during the prior year, 88 percent received money, and 69 percent received significant amounts (defined as \$30 or more). Almost half (49 percent) reported their children as their main source of support (Knodel et al. forthcoming-a).

One result of this familial system of intergenerational support exchanges is that substantial proportions of adult children live with or near to parents. If a coresident child marries and moves out of the parental household it is often to a dwelling in the same compound or community. According the nationally representative 1995 Survey of Welfare of Elderly in Thailand (SWET), one fourth of children aged 15 and over of parents aged 50 and over coresided with their parents and another fourth lived either adjacent to parents or in the same local community (original tabulations). Moreover, rural Thais tend to maintain strong attachments to their community of origin, especially when their parents remain there. This is evident from the data collected in the 1995 SWET which indicates that almost 90 percent of adult children who lived outside the local community of their parents returned to visit their parents during the prior year and two-thirds of those who returned had visited at least several times.

In brief, in comparison with more affluent countries, Thailand shares important characteristics with other developing country settings that are likely to be critical for understanding the implications of the AIDS epidemic for older persons in the countries having the highest levels of HIV and AIDS. Thus the findings of the present study have considerable relevance for other developing countries that are also experiencing an increasing burden of AIDS.

Data and Methods

Key Informant Approach

Drawing a reasonably unbiased and sufficiently large sample of cases poses formidable challenges for any attempt to quantitatively study the impact of AIDS on parents of infected persons (Mullan 1998). The difficulties arise both from the need to be able to identify the population of appropriate cases and the sensitive nature of subject matter being investigated. The strategy we employed to minimize these problems was to interview key informants in the public health system to provide individual case information. We selected informants who were likely to know who in their local area was ill with or had died from AIDS, along with basic information about them: age, sex, marital status, existence of dependent children, living status of parents at time of illness, if and how long the person lived with a parent, change of residence during illness, and who provided care. For a subset of these cases whom the key informant knew best, we asked supplemental questions about economic status, burdens of caregiving, financial arrangements, economic impact on the family, and ages, health and location of parents, and community reaction. Three forms were used to collect the information and are included as appendices (Appendix A shows the general form used for the provinces; Appendix B shows the general form used in Bangkok; Appendix C shows the form with supplemental questions for the subset the informant knew best). All interviews were conducted by the principal investigators (the authors of this report) and occurred primarily during the first half of 1999. To protect confidentiality, names of individual cases were not recorded.

We collected information from key informants in 85 sites in 8 provinces and Bangkok. The provincial samples were drawn from all major regions of Thailand and included both rural and urban settings in each province. The specific provinces were Rayong and Petchaburi in the central region, Khon Kaen and Ubon Ratchatani in the northeast, Chiang Mai and Chiang Rai in the upper north, Phichit in the lower north, and Phuket in the south. To maximize the number of cases for which we could obtain information, we chose provinces with relatively high AIDS levels for the region based on HIV infection levels among military recruits during 1991-98. Nevertheless, because there is sharp regional variation in the level of the epidemic, as Table 1 shows, the selected provinces differ considerably in the percentages HIV positive among recruits, ranging from 8-9 percent in the two upper northern provinces to under 2 percent in the two northeastern ones. Likewise, the percentage HIV positive among pregnant women going for antenatal

care varies by five-fold from almost 5 percent to less than 1 percent among the selected provinces.

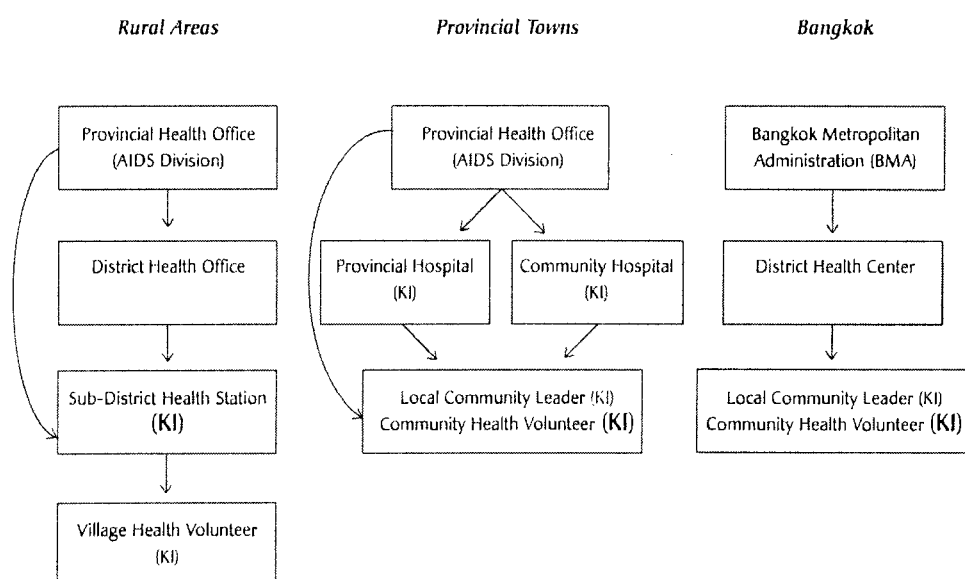
Table 1. Indicators of levels of the AIDS epidemic in the sampled provinces

	% HIV+ among Army Recruits 1991-1998	% HIV+ among antenatal care clients 1991-1997
Chiang Rai	8.8	4.8
Chiang Mai	7.6	4.3
Rayong	6.5	4.9
Phuket	4.1	1.4
Petchaburi	3.8	3.5
Bangkok	2.7	1.1
Phichit	2.1	0.9
Ubon	1.8	0.9
Khon Kaen	1.7	0.8

Sources: Armed Forces Research Institute of Medical Sciences; Epidemiology Division, Ministry of Public Health.

Figure 1 indicates the types of key informants interviewed and the routes through which they were contacted for rural, provincial urban, and Bangkok sites. The mix and importance of particular types of key informants differed among settings. Key informant sources are designated by the initials KI, with major source for each of the three types of settings designated in large, bold type.

Figure 1.
Routes of Access to Key Informants (KI)



For most rural sites, informants were typically staff of community (*Tambol*) health stations, the lowest level facility in the Thai Public Health system. We chose sites where a staff member was either a local person or in place long enough to know the community well. The selected stations were responsible for a median of 1100 households. Most informants appeared confident in their ability to identify AIDS-related deaths within their local area of responsibility.¹ Identification of currently symptomatic cases was probably less complete since the onset of illness is less likely than a death to become known to the key informant. The key informants' information came from many sources including notification from higher level facilities, visits to the health station by the person with AIDS or their relatives, home visits, the extensive network of village health volunteers, and funerals. Occasionally, we turned to village health volunteers in situations where the health station official indicated s/he lacked sufficient local knowledge to provide the information we needed.

¹ For each of the cases for which the informant provided supplementary information, we asked how confident the informant was about the information provided. For 63 percent of the cases the informants indicated high confidence, for 27 percent reasonable confidence and for 9 percent low confidence. Since informants were encouraged to indicate freely when they did not know the answer to a question, cases in which low confidence was indicated tend to have more missing answers to specific questions and thus are disproportionately excluded from specific analyses.

For the 60 percent of sites that maintained registers of deaths, we had informants review the registers to help identify AIDS-related deaths (regardless of the stated cause). Elsewhere the informants relied on memory. To assist them in this task, we instructed informants to first think about cases in each of the subdivisions of their area of jurisdiction and then to write down the names of each case for review later. Only then did we ask about providing details on any one case. This seemed to be a useful approach to systematically jog their memory.

Given differences in the public health system in urban areas (e.g. community health stations generally do not exist) and the greater anonymity of urban settings, we drew urban informants from more varied sources. Both in provincial urban settings and in Bangkok the most important source was the corps of urban neighborhood health volunteers. We also included community leaders in both settings and in provincial urban areas we occasionally drew on welfare workers, home visiting nurses, and health personnel in provincial and community hospitals.

One indication that the key informants had accurate information on the AIDS situation in their areas comes from the answers they provided to a question that asked them to assess the proportion of deaths to working age adults that is attributable to AIDS in their area of their responsibility. This question was asked at most provincial sites but not in Bangkok (because of the very limited size of localities and small numbers of cases for which Bangkok key informants reported). By averaging the assessments for all sites in a province, we can obtain a provincial level estimate. These provincial averages range from a low of 17 percent to as high as 70 percent and correlate .85 with the provincial levels of HIV prevalence among army recruits and .89 with HIV prevalence indicated for women going for antenatal care (based on the eight provinces for which we collected the information).

A key informant approach carries potential risks. Informants might be selective in their familiarity with cases in ways that could bias results. For example, they might be more familiar with cases who had lingering illness and higher care needs or who were cared for by an extended family compared to those who died after an acute first episode or were cared for more privately (e.g. by only a spouse). Likewise they might be more familiar with cases of longer established members of the community or with cases with more social or medical needs. Such biases are probably more likely to effect reporting of cases who are currently ill than those who already died since a death becomes quickly and widely known and funerals are quite public affairs in Thailand. Additional biases could arise from presumptions made by the key informant rather than actual observations about the cases. For example, key informants may assume mothers are generally more likely to provide caregiving than fathers and thus report the mother as the main caregiver even when they do not have direct knowledge that this is the true for the particular case. When studying a stigmatized disease such as AIDS, however, these risks need to be weighed against the likely more serious biases that characterize common alternative approaches such as those based on volunteers, self-identified cases, or attempted random samples that suffer from extremely low response rates (Levy and Albrecht, 1989). Moreover, as shown

below, the sample we obtained is quite similar to AIDS cases in general on numerous important dimensions relevant for our analysis.

To keep interview length manageable, we usually limited the number of cases for which basic information was requested to a maximum of 20 per site who died locally of AIDS and 5 who were currently symptomatic and living in the community. We asked the supplemental questions described above for a maximum of six adult cases, giving priority to those who had already died. When the potential cases exceeded our limit, we gave precedence to those who were adults (age 15+), who died most recently, and for whom the informant felt more confident about the information being requested.

We also asked more limited information about cases who had presented symptoms while in the community but left before dying and cases whose parents lived in the community but who died elsewhere. We obtained basic information on living arrangements and care-taking for 1069 cases who were currently ill with or had died of AIDS (locally or elsewhere). This includes a subset of 286 cases for which the supplemental questions were asked.

The number of sites visited in each province and Bangkok and the number of cases of each type for which some information was provided is shown in Table 2. For the purpose of the quantitative analysis presented in this report, we restrict consideration to the 963 adult cases (including 285 with supplemental information) who either were still present with symptoms (195 cases) or died locally (768 cases). The restriction to these cases is made for two reasons. Most importantly, persons with AIDS who left the locale or who were elsewhere during their entire illness would theoretically have twice the chance of being included in our sample, once at their place of origin and once at their place of destination, than persons who were present or died in the locale. Secondly, less information was asked about the 106 excluded cases because informants generally did not know many details about them for the period they were not in the community.

Depending on the particular results presented in the following tables, the unit of analysis can either be the AIDS case or the parent of the AIDS case. The labeling of each table makes clear which unit of analysis is being used. When the unit of analysis is the parent, we draw the data from the subset of AIDS cases for which supplemental information was collected about the parents. The total number of parents for whom such information is available is 393, however the analyses presented here are limited to the 360 parents of cases who had already died of AIDS (and thus excludes the 33 parents of PWAs still alive at the time of data collection).²

² This is greater than the number of cases for which supplemental information was collected reflecting the fact that some of the cases had two living parents (at the time of illness) and information is available for both parents in these cases.

Table 2. Number of sites visited and number of individuals for whom data was provided by key informants

Province	Sites visited	Number of individuals for whom data was collected				
		Basic data				Supplemental data (for subset KI knew best)
		Total	Died of AIDS locally	Living with AIDS locally	Left before dying of AIDS (a)	
Rayong	10	234	179	50	5	25
Chiang Mai	7	179	142	30	7	40
Chiang Rai	7	167	138	29	(b)	45
Khon Kaen	7	65	44	16	5	35
Petchaburi	9	109	91	14	4	42
Phichit	13	99	69	25	5	35
Phuket	11	78	49	14	15	30
Ubon Rachatani	11	86	54	23	9	25
Bangkok	10	52	23	8	21	9
Total all cases	85	1069	789	209	71	286
adult cases (c)	85	1032	768	195	69	285

Notes: a) Includes 9 cases who moved away before being ill and died elsewhere but whose parents still lived in the site. (b) Information about persons who left before dying was not collected in Chiang Rai. (c) Adult cases are defined as age 15 and above.

In cases where the unit of analysis is the AIDS case and the focus is specifically on the involvement of parents, results are presented both for all cases and for cases who have a living parent. In the latter situation (i.e. for results based on AIDS cases who had a living parent), we adjust the results to allow for the 8 percent of cases for whom the informant was uncertain if a parent was alive (typically involving cases who were non-local spouses of local persons). In many of these cases the parents are likely to be alive. However since informants are probably more likely to know of living than dead parents (e.g. the parents may have visited the community), these unknown cases are probably skewed towards persons with deceased parents. Thus in the calculations we assume that the proportion with a living parent is two-thirds that of the equivalent 5-year age group based on cases for whom the parents' living status is known. Given the small percentage of cases involved, results are only minimally affected by this assumption and adjustment.

Sample Comparability

Our sample based on key informant information is clearly not designed to be nationally representative in any statistical sense. Nevertheless, it is instructive to compare it in terms of important characteristics that are likely to bear on our results with what would be expected from a truly representative sample. To do this we draw on independent external sources of information that are intended to be nationally representative, primarily the national registry of AIDS cases maintained by the Ministry of Public Health and the 1994 National Survey of the Elderly conducted by the National Statistical Office (no date). In the following comparisons, we focus on cases reported to the Ministry for 1997-98 since our sample is skewed towards recent cases reflecting the selection process and the timing of fieldwork.

Two-thirds of the adult cases are drawn from rural settings, with the remainder divided almost equally between officially designated municipal areas and peri-urban areas (either on the fringes of municipal areas or urbanized in appearance). Although information on the rural-urban distribution of registered AIDS cases is not available, we note that the distribution of our sample closely resembles that of the national population in general.³

With regard to sex distribution, 26 percent of our total adult sample of persons who are ill with or died of AIDS are women compared to 23 percent among nationally registered cases reported for 1997-98. Thus overall our sample is only modestly more weighted towards women compared to all reported cases. The representation of women among the subset of cases that were currently symptomatic but had not yet died, however, is particularly high (43 percent) and accounts for the higher percentage of women in the overall sample. This may reflect a greater ease for local health personnel in identifying symptomatic women than men. In many cases, the women contracted HIV from their husbands whose earlier death alerts the informant of the possibility the wife may be infected and to be on the lookout for symptoms. Also pregnant women are routinely tested as part of antenatal care and local health personnel sometimes learn when a woman tests positive. This overrepresentation of women does not characterize the sample who died of AIDS because death, as opposed to onset of symptoms, quickly becomes public knowledge regardless of sex.

Figure 2 presents additional comparisons. Panel A shows that the age distribution of persons living with or who died of AIDS in our sample is almost identical to that of nationally reported AIDS cases. Panel B indicates that the marital status distribution of the sample is reasonably consistent with that of nationally reported AIDS cases. In both,

³ Exact comparisons with official statistics cannot be made since our classification is based on a combination of official definitions (for municipal areas) and observation (for rural and peri-urban areas). However, we gauged similarity with the national distribution by a comparison to the nationally representative household sample of the 1994 the National Survey of Elderly which indicates 70 percent of the population was rural and 30 percent were either in officially designated municipal areas or sanitary districts (essentially peri-urban areas).

married persons are clearly the most common, followed by single persons. Our sample, however, has a higher proportion of formerly married persons than nationally reported AIDS cases. This reflects in part the modestly higher proportion of women in our sample, among whom a much higher proportion (42 percent) are widowed separated or divorced than among the male AIDS cases (14 percent).

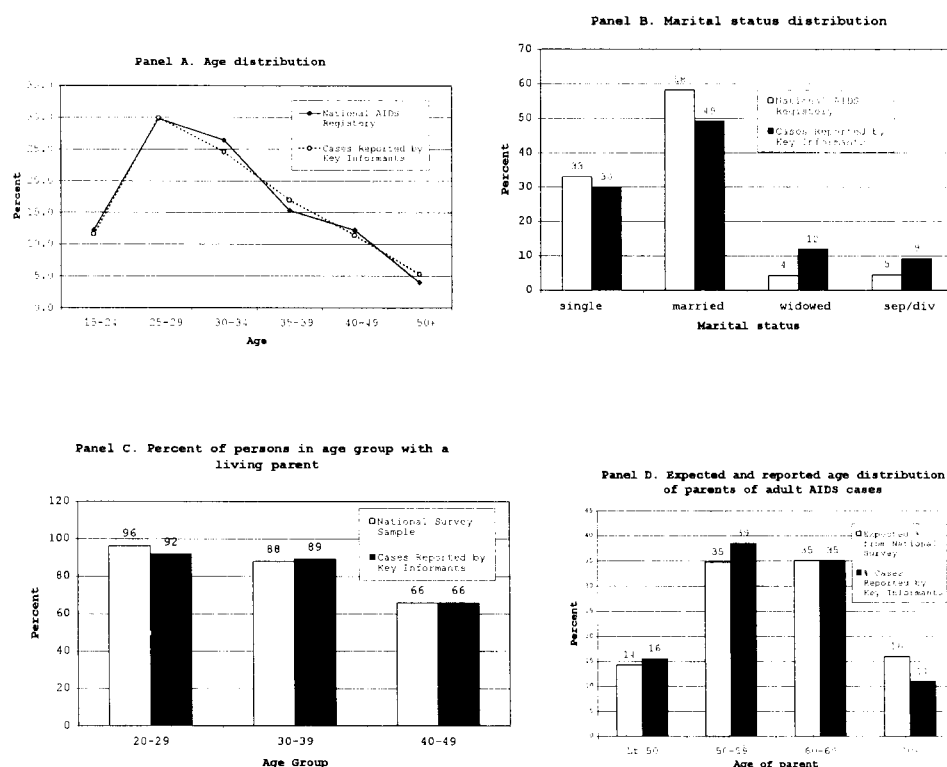
Panel C shows that the proportions of our sample of AIDS cases with a surviving parent are similar to the proportions in the equivalent age group with a living parent among the general population as found in 1994 the National Survey of Elderly.⁴ For the purpose of this comparison, our sample results are adjusted to allow for the 8 percent of cases for whom the informant was uncertain whether a parent was alive. Finally, panel D indicates that the age distribution of the parents of the AIDS cases in our sample as reported by the key informants is very similar to what would be expected based on the age distribution of parents of adults in the general population who are in the same age groups as the adult AIDS cases in our sample.⁵

In brief, these comparisons taken together suggest that cases reported by the key informants resemble remarkably well the national population of recent AIDS cases in Thailand on several important dimensions. Cases reported by our key informants thus should provide a reasonably typical sample for analyses relating Thai adults ill with or who died of AIDS and their parents.

⁴ Although, as the title implies, the main purpose of the survey was to collect information on older persons (aged 50+), it also included questions directed to a nationally representative sample of all households regardless of the presence of older household members.

⁵ The expected age distribution of parents of adults with AIDS in our sample was calculated from a matrix which showed the percentage age distribution of living mothers and living fathers for adults in each age group in the general population (as provided in the 1994 Survey of Elderly in Thailand). By weighting that matrix by the proportionate age distribution of AIDS cases in our sample, we obtain the expected age distributions of living mothers and fathers assuming that the AIDS cases in each age group had living parents of similar ages as the equivalent age groups of adults in the general population. By combining mothers and fathers, we obtain the expected age distribution of parents.

Figure 2. Comparison of Selected Characteristics of Study Sample Based on Information from Key-Informants with Expected Characteristics Based on Independent External Sources



Sources of external data: Special tabulations from Thailand, Ministry of Public Health, AIDS Division (Graphs A and B); Original tabulations from Thailand, National Statistical Office, 1994 Survey of Elderly in Thailand (Graphs C and D).

Note: Estimates in Panel C are adjusted for cases for which the key informant did not know the living status of the parents (see text). Estimates in panel D compare the age distribution of parents of adults in the general population who are in the same age groups as the adult AIDS cases in our sample.

Inclusion of Return Migrants

For persons with AIDS, living and caretaking arrangements often change during the course of the illness. Many are able to care for themselves initially but at later stages require assistance. Thus some who live away from their place of origin at the onset of symptoms return when they can no longer earn a living or need care assistance (Brabant 1994; Ellis and Muschkin 1996; Sankar et al. 1998). Among our total adult sample, 37

percent of those who had died had returned to their place of origin after becoming ill and the large majority (77 percent) of these moved in with parents or adjacent to them. A substantial share (at least half) of those who moved back and did not live with or next to parents had no living parent. Some of them may have moved in with older generation relatives but we do not have information about this. Some return migrants waited until the illness was very advanced before moving.

For example, about a third (32 percent) of those who returned when ill lived no longer than a few months, including some who died after just a few weeks or even a few days following their return. In contrast, rarely were cases reported to have left their place of origin to die elsewhere.

Such a high return rate is quite plausible in the Thai context. Unless migrants are married and their spouse remains with them to provide care and financial support, they often have nowhere else to go. Thai hospitals shy away from long term care of AIDS cases and hospices have limited capacities. Moreover, many persons with AIDS may have strong personal emotional reasons for wanting to be at home to die. Nevertheless, it is important to consider if our sample design could potentially bias our results in this respect. In Thailand, many young adults migrate from their parental home in the provinces to find work in urban centers, especially Bangkok. Although Bangkok and other urban places are in our sample, the number of cases from these places, the non random nature of our sampling of sites within urban areas, and/or selective familiarity on the part of key informants with cases involving native persons could potentially skew our results towards cases who never left their rural villages and those return to their place of origin. If adults who migrated to Bangkok (or elsewhere) and died of AIDS without returning to their parental home before death are large in number and substantially under represented in our data, this would result in our overestimating the extent of parental involvement with AIDS.

We followed several strategies to assess this problem and they all suggest that the extent of any such bias is likely to be small. First, we interviewed staff of four major organizations who assist large numbers of persons with AIDS in Bangkok. They consistently reported that despite common initial hesitancy to reveal their situation to their parents, most migrants eventually return home, especially once they became too ill to work even if they are married. Second, we identified 18 cases in the Bangkok sample sites who were migrants from the provinces. Two thirds were reported to have returned to their provincial home after becoming ill. Several others left the community to destinations unknown to the informant; some or all of these could have returned to their parental home. Third, when we directly asked provincial key informants about this matter, almost all agreed that the vast majority of AIDS cases would return to be with their parents before dying. Cases of adult children who died away from the parental home were reported in only a fourth of the provincial sites and in about half of these sites, only one case was known. Of course, cases of non-return by their very nature may not be known to the key informant. Still all the evidence we have, along with the generally free

flow of information that typifies most rural communities in Thailand, leads us to believe this is a rare event.

The link between migration and stage of illness has implications for estimates of the percentages of parents who coreside with AIDS inflicted adult children and who contribute to caregiving. Because of return migration during the illness, the extent of parental involvement is fully evident only for cases who have already died of AIDS. We thus focus much of the analysis on persons who have died of AIDS and include both adult children who were living in the area in which they died when symptoms first appeared and those who returned after the onset of symptoms.

Results

Living and caregiving arrangements

Several basic measures of living and caregiving arrangements of AIDS cases in relation to older generation persons are summarized in Table 3. They refer to the current situation for those still living and to the terminal stage of illness for those who died. For the measures relating to parents, additional results are shown conditioned on the availability of a living parent, adjusted for the small proportion of cases for whom the informant did not know if a parent was alive as described above. Such an adjustment is necessary since cases for whom the living status of parents is unknown are necessarily selective of those who did not coreside with parents or receive parental care (if they had, it would be known that a parent was alive). Ignoring these cases would artificially inflate the indicated levels of parental involvement.

As expected from the fact that substantial numbers of persons with AIDS return home only at later stages of illness, the measures consistently show higher percentages of parental and overall older generation involvement for cases who already died of AIDS compared to currently symptomatic cases. An even greater difference is evident between these two groups for the caregiving measures. This likely reflects the increasing need for assistance as the illness progresses. Indeed half of the currently symptomatic cases were still caring for themselves while almost all who died were given care by others (not shown).

Table 3. Indicators of parents' and older generation persons' role in living arrangements and caregiving for persons aged 15 or older who died of AIDS or are living with symptomatic HIV

	Persons who died of AIDS		Persons with symptomatic AIDS	
	Mean incidence	Standard error	Mean incidence	Standard error
All Cases				
% coreside with parent when ill	58.8	1.8	49.0	3.6
% coreside with or live next to parent when ill	66.5	1.7	56.7	3.6
% for whom parent provided care	64.5	1.8	34.8	3.5
% for whom parent was a main caregiver	49.7	1.8	26.7	3.2
% for whom any older generation person provided care	70.2	1.7	38.5	3.6
% for whom any older generation person was a main caregiver	53.8	1.8	28.9	3.3
Number of cases (a)	754/738		194/187	
Cases with at least one living parent –adjusted estimates(b)				
% coreside with parent when ill	69.7	1.8	60.6	3.8
% coreside with or live next to parent when ill	78.8	1.6	70.1	3.6
% for whom parent provided care	76.9	1.7	42.1	3.9
% for whom parent was a main caregiver	59.3	1.9	32.4	3.7
Number of cases (a)	659/645		164/162	

Notes: (a) The first number refers to the number of cases with non-missing values for the two living arrangement measures and the second number refers to the number of cases with non-missing values for the two caregiving measures. (b) Estimates are adjusted for cases for which the key informant did not know the living status of the parents. See text.

Older generation persons in Thailand are commonly involved with the living and caretaking arrangements of persons with AIDS. A majority (59 percent) of those who died of AIDS coresided with a parent at the terminal stage. Moreover, two-thirds either coresided or lived next door, reflecting the fact that married children, especially in rural Thailand, often live in the same family compound (Knodel and Saengtienchai, 1999). These percentages are even higher (69 percent and 79 percent respectively) when only cases with a living parent are considered.

Caregiving also commonly involves parents. Parents provided care for almost two-thirds of those who died of AIDS and were the main caregiver for half. For those cases with a living parent, more than three fourths received some care from a parent and for almost 60 percent a parent was a main caregiver. Even when a parent was not involved, other older

generation relatives sometimes played a caregiving role. Thus a total of 70 percent of adult AIDS cases were cared for by someone of the older generation if both parents and relatives are taken into account.

Characteristics of AIDS Cases

Table 4 focuses on how demographic characteristics of adults who died of AIDS relate to coresidence with parents and having a parent as a main caretaker (the two more intensive measures of parental involvement). Results are shown both for all adults who died and for those with a living parent (corrected to allow for cases where the living status of the parent is unknown as explained above). In addition to simple bivariate associations, results are also provided that are statistically adjusted through logistic regression. Adjusted results indicate the association with each characteristic net of the influence of the other characteristics in the table and are presented as mean predicted probabilities to facilitate interpretation.⁶

The unadjusted results both for all cases and cases conditioned on having a living parent show that both coresidence with a parent and having a parent as a main caretaker decrease with age, especially for the oldest. The negative associations with age are somewhat less pronounced when conditioned on having a parent alive but are still quite strong. Statistical adjustment for associations with the other variables only modestly attenuates the negative relation with age. The sex of the person dying with AIDS shows little relationship with coresidence with a parent but women seem modestly more likely to have a parent as main caretaker than do men. Neither conditioning on having a parent alive nor statistical adjustment for the other variables has much impact on the weak association with sex.

A quite strong relationship exists between parental involvement and the marital status of the person who dies of AIDS. Indeed, a substantial majority of single and separated or divorced adult children who died of AIDS lived with a parent at the terminal stage of illness. Likewise parents served as main caregivers for most of these children. Widowed and currently married cases were considerably less likely to live with parents or have a parent as a main caregiver. This lower level of parental involvement for widowed cases is in large part due to their lower chances having a living parent (given that they are considerably older than other cases on average – see following table). Once the statistically unadjusted results are conditioned on availability of a living parent, the tendency to coreside with a parent when ill among widowed is more similar to separated or divorced cases than to married ones. Even for over all cases, however, substantial

⁶ To derive adjusted percentages for each particular category of the variables shown, we first calculated a predicted probability for each individual included in the analysis on the basis of the logistic regression coefficients. We assumed that all individuals fall into the particular category under consideration but retain their actual values with respect to all other control variables. Then we calculated the adjusted percentage as the mean of the predicted probabilities for that category for all individuals included in the analysis.

Table 4. Indicators of parents' role in living arrangements and caregiving for persons aged 15 or older who died of AIDS, by demographic characteristics of the AIDS case, unadjusted and adjusted by logistic regression

Demographic characteristic of person who died of AIDS	N of cases (a)	% who lived with a parent when ill			% for whom parent is main caregiver		
		All cases		1+ parent alive (b)		All cases	
		Unadjusted	Adjusted	Unadjusted	Adjusted	Unadjusted	Adjusted
Age			(p = .000)		(p = .000)		(p = .003)
15-29	304-275	71.1	68.8	77.7	75.4	59.7	55.9
30-39	321-292	61.1	61.4	67.6	68.2	53.7	54.6
40+	129-78	24.0	27.2	45.7	50.1	17.7	21.2
Sex			(p = .533)		(p = .656)		(p = .045)
male	587-499	59.4	58.9	70.0	69.2	48.6	47.8
female	167-146	56.3	56.4	68.5	67.2	53.6	54.7
Marital status			(p = .000)		(p = .000)		(p = .000)
single	242-213	81.0	60.2	90.5	70.6	76.6	51.5
sep./divorced	64-53	68.8	57.3	82.2	62.7	66.1	48.1
widowed	68-51	48.5	42.7	71.1	50.9	47.1	33.7
married	373-322	44.0	43.9	52.5	52.6	29.3	29.5
Residence			(p = .000)		(p = .002)		(p = .001)
rural	516-446	64.0	62.7	73.4	72.3	54.2	53.2
urban	238-199	47.4	48.6	60.6	60.6	40.4	41.1
							(p = .008)
							61.5
							51.5

Notes: The figures adjusted by logistic regression represent the mean predicted probabilities taking into account the other demographic characteristics included in the table. All characteristics are treated as categorical variables in the regression. The *p*-values indicate statistical significance of the set of categories based on the Wald statistic. (a) The range represents the maximum and minimum number of cases on which results in each row are based. (b) Estimates are adjusted for cases for which the key informant did not know the living status of the parents. See text.

shares of both widowed and married persons dying of AIDS lived with or were taken care of by a parent in the final period. Given the association between age and marital status, it is not surprising that the extent of marital status differentials is reduced after statistical adjustment. Nevertheless even the adjusted association remains pronounced. Finally, living with a parent when ill and having a parent as a main caregiver is more common for rural than urban cases. This remains the case both when conditioned on availability of a living parent and after statistical adjustment for the other variables.

Parental Versus Other Caregivers

Parents of course are not the only persons who provide informal care to adult persons with AIDS (PWAs). Table 5 shows the frequency with which a parent serves as caretaker for adults who died of AIDS compared to other persons. Results are shown according to the sex and marital status of persons who died of AIDS. To aid in interpretation of the results, the table also shows the mean age of death and the percentage who have a living parent (which are obviously related). In general, men and women who die of AIDS differ only modestly in these respects. However, some substantial differences are evident by marital status in both respects. As noted above, widowed persons dying of AIDS are considerably older than average and single persons are somewhat younger.

Overall, parents are clearly the most common caregivers, well ahead of spouses who take second place. The main difference in the configuration of caregivers for men and women with AIDS is with respect to the percent for whom a spouse was a caretaker. Men are much more likely to have been cared for by their wives than the reverse. Given that for both men and women who died, about half were currently married (not shown), the difference reflects the greater tendency for women than men to be caregivers. Also, currently married women PWAs may be more likely than married male PWAs to have a spouse who is already ill.

The configuration of caregivers varies considerably with the marital status of the person who died of AIDS. For those who are still single at death, a parent was a main caregiver in over three-fourths of the cases and provided at least some care for over four-fifths. Parents were also the most common caregivers (main or otherwise) for separated and divorced as well as for widowed children. For widowed cases, however, children of the person who died were very common compared to other cases. This is likely related to the older age at death of widowed cases which results in their being more likely to have children old enough to contribute to caregiving but less likely to have a living parent to provide caregiving.

Table 5. Mean age at death, percent who had a living parent, percent who lived with a parent, and percent who had caregivers of particular types among adults dying of AIDS, by sex and marital status of person dying of AIDS

	All cases	Sex		Marital status			
		Male	Female	Single	Separated /divorced	Widowed	Currently married
N of cases (a)	738(b)	570	168	235	62	70	365
Mean age at death	33.0	33.4	31.6	29.8	34.6	40.0	33.5
% having a living parent (c)	82.3	83.4	78.6	88.3	82.0	65.2	81.3
% for whom main caregiver was:							
Parent	49.7	48.6	53.6	76.6	66.1	47.1	29.3
Other older generation person	4.2	3.9	5.4	5.1	1.6	7.1	3.6
Spouse	31.6	35.3	19.0	--	--	--	63.8
Sibling	10.8	10.9	10.7	15.7	22.6	11.4	5.8
Child/child-in-law	3.8	2.6	7.7	--	3.2	30.0	1.4
Other	3.1	2.8	4.2	5.1	4.8	5.7	1.1
% for whom any caregiver was:							
Parent	64.5	64.9	63.1	80.9	69.4	54.3	54.5
Other older generation person	7.7	6.8	10.7	7.7	3.2	7.1	8.8
Spouse	35.2	38.8	23.2	--	--	--	71.2
Sibling	26.0	26.0	26.2	37.9	45.2	27.1	15.3
Child/child-in-law	7.0	6.0	10.7	--	4.8	32.9	7.1
Other	7.7	6.5	11.9	8.9	12.9	18.6	4.1

Notes: All results refer to the situation at the terminal stage of illness. The sum of the percents of each type of caregiver exceeds 100 since for some persons dying of AIDS, the key informant reported more than one type of caregiver including 5 percent of cases for whom more than one type of main caregiver was reported.

-- = not applicable.

Refers to the number of cases with caregiving information; mean age at death and the percentage with a living parent is based on a slightly larger number of cases. (b) Includes 6 cases of unknown marital status. (c) Estimates are adjusted for cases for which the key informant did not know the living status of the parents. See text.

The one group for whom parents were not the predominant caregivers is persons who were currently married when they died of AIDS. Spouses served as a main caregiver for almost two-thirds of these cases and provided at least some care for over 70 percent. Still, even for married AIDS cases, parents are frequently involved as a main care taker and provide at least some care for more than half. A third of married cases had returned from elsewhere since the onset of illness (not shown). A few returned because both spouses were ill. More commonly, however, the return appears prompted by the need for caretaking assistance by the spouse who was well. This is suggested by the fact that in over 40 percent of cases where a married couple returned, a parent acted as a main caregiver and in almost two-thirds assisted in caregiving (not shown).

So far results have been based on the full set of all cases reported by the key informants. For a more detailed portrayal of the impact of AIDS on the family and particularly the parents, we turn to the supplemental information collected on the subset of cases the key informant knew best and about whom we asked additional questions (appendix C is the supplemental questionnaire form). The remainder of the analysis is based on this subset of cases. In addition, because the full impact on the family including the parents resulting from having an adult child that suffers from AIDS is not evident until the child dies, most analyses are limited to cases who already had died at the time of the data collection. In general, the subset of cases resembles fairly closely the full set of cases of persons who died of AIDS in terms of basic characteristics such as rural or urban residence, gender, age, marital status, and the involvement of parents in living and caretaking arrangements during illness.⁷

Caregiver Characteristics

The characteristics of the parents of adults who died of AIDS and how they relate to involvement with living and caretaking arrangements are shown in Tables 6 and 7 and refer to parents who were alive at the time of the child's death. Table 6 shows the distribution of parents according to selected characteristics of interest for all the parents and for those with different types of involvement with the child with AIDS. The results indicate that the large majority of parents (85 percent) were age 50 or over at the time their child died and almost half of these were 60 or older. Consistent with lower female mortality, more mothers were alive than fathers. Most were described as being in good health and three fourths as average or above average in terms of economic status.

The characteristics of parents who coresided with their AIDS inflicted child are generally similar to the total sample of parents who were alive when their child died of AIDS although the sex distribution is modestly more skewed towards mothers. In contrast, those who provided care differ noticeably in their age and sex distributions from those who did not. Caregiving parents, and especially those who served as main caregivers,

⁷ For example, a comparison of all cases of persons who died of AIDS and those with supplemental information yield respectively the following results: median age, 31 vs. 31; percent female, 22 vs. 26; percent currently married at the time of death, 50 vs. 52; percent rural, 69 vs. 67; percent lived with parents when ill, 59 vs. 59; percent for whom a parent was a main caregiver, 50 vs. 52.

tend to be younger than parents of AIDS cases in general. Even so, two-fifths of main caregivers were 60 or older. Caregiving parents and particularly main caregivers are overwhelmingly mothers. Caregivers differ little from the overall sample in their health and economic status distributions.

Table 6. Percentage distribution of all parents of adult children who died of AIDS, of parents who coresided with the child, of parents who gave any care to the child, and of parents who gave main care to the child, according to selected characteristics of the parent

Characteristic of parent	All parents	Coresident parents	Providing any care	Main care-givers
Total	100	100	100	100
Age				
< 50	14.8	16.5	15.9	17.4
50-59	37.2	39.3	40.7	43.1
60-69	37.2	35.7	35.8	33.3
70+	10.7	8.5	7.5	6.3
Sex				
Father	41.9	37.7	30.3	15.9
Mother	58.1	62.3	69.7	84.1
Health status				
Good	79.4	80.3	80.9	78.5
Minor problem	9.8	9.0	9.8	11.8
Poor	10.8	10.8	9.3	9.7
Economic status				
Good	23.2	22.1	23.4	20.9
Average	50.2	52.7	51.4	51.8
Poor	26.6	25.2	25.2	27.3
N of cases(a)	360-315	228-222	228-218	145-139

Notes: Results are based on the subset of cases for whom supplemental information was collected. The parental characteristics refer to the time of the child's death. Results excludes cases with unknown values for each characteristic.

- (a) The range represents the maximum and minimum number of cases on which results for each set of characteristics are based.

Table 7 indicates the proportion of parents who coresided with, provided any care to, or were main caregivers for the adult child who died of AIDS by the same characteristics of interest examined in the previous table.⁸ Close to two thirds of parents of adult children who died of AIDS lived with the child during the illness, a similar proportion provided care, and about half served as a main caregiver. The age of the parent is generally inversely related to coresidence with and caretaking of the ill adult child, with the oldest parents particularly less likely to provide care. The sex of the parent is significantly associated with all three measures of involvement. Mothers are somewhat more likely than fathers to coreside with an adult child with AIDS and very much more likely to be involved in caretaking. The health status of the parent shows no consistent relationship with coresidence. Although there is not a consistent gradient apparent between parents health and the caregiving measures, those in poor health are less likely than others to provide care. This suggests that minor health problems are not a barrier for parental caregiving but major health problems are. The lack of a more consistent gradient could also be a reflection of the small numbers of parents reported to be in less than good health combined with measurement error due to the subjective nature of the measure.

Burdens of Caregiving

The key informants were asked if providing care for the person with AIDS was a serious burden for the caregiver. If the reply was affirmative, the informant was further asked if the caregiving resulted in physical, emotional, or financial strains or demanded constant attention (and thus creating time strains). Given the very subjective nature of these judgements, this is an area where the information from key informants may have more questionable validity than information that is less subjective. The results may reflect the expectations of key informants as much as their actual knowledge of the specific cases. Nevertheless, the opinions of the key informants are likely to reflect at least their generalized experiences with AIDS cases even if not always based on directly on the specific case in question.

⁸ Results are adjusted for the small number of parents for whom information on a particular characteristic is lacking (while sex is known for all, for 11-12 percent of parents age, health or economic status is lacking). Since cases for whom such information is unknown are skewed heavily towards parents who lived outside the local community and thus were not involved in the living and caretaking arrangements when their child was ill, ignoring them would artificially inflate the indicated levels of involvement for each characteristic category (except sex categories). Thus for the purpose of these calculations, we assume that cases with unknown values of a particular characteristic are distributed similarly to those for whom the characteristic is known. Given the small number of cases involved, this is unlikely to bias results in any meaningful way.

Table 7. Adjusted percent of parents who coresided with, gave any care, and gave main care to adult children who died of AIDS, by selected characteristics of the parent

Characteristic of parent	Co-resided	Gave any care	Gave main care
Total	63.3	63.3	40.3
Age			
< 50	70.6	68.0	47.2
50-59	66.8	69.3	46.4
60-69	60.8	61.0	36.1
70+	50.1	44.4	23.5
Significance level	n.s.	*	*
Sex			
Father	57.0	45.7	15.2
Mother	67.9	76.1	58.4
Significance level	*	***	***
Health status			
Good	64.1	64.5	39.8
Minor problem	57.5	62.9	48.3
Poor	63.2	54.8	36.3
Significance level	n.s.	n.s.	n.s.
Economic status			
Good	60.3	63.9	36.2
Average	66.5	64.9	41.6
Poor	60.0	60.0	41.3
Significance level	n.s.	n.s.	n.s.
N of parents(a)	360-315	360-315	360-315

Notes: Results are based on the parents of the subset of cases for whom supplemental information was collected. The parental characteristics refer to the time of the child's death. Results are adjusted in the sense that parents with unknown values for a particular characteristic are distributed proportionately according to the distribution of parents with known characteristics. Statistical significance is based on parents with known values for each characteristic and measured by the Pearson Chi-square test. Given that the sample is not a probability sample, the levels of significance can only be considered as illustrative: n.s. = not significant at the .05 level; * = $p < .05$; ** = $p < .01$; *** = $p < .001$.

- (a) The range represents the maximum and minimum number of parents on which results for each set of characteristics are based.

Results are shown in Table 8 with comparisons between cases based on the role parents took in caregiving. Overall caregiving was reported to be a serious burden in 79 percent of the cases of adults who died of AIDS. For cases where a parent was a main caregiver, however, the share is noticeably higher (87 percent). For these same cases, emotional strain was the most commonly cited burden. Caregiving also appears to be more likely to involve physical, emotional and time strains when a parent is the main caregiver than in cases where the parent is not. In addition, financial strain is reported for a higher percentage of cases when a parent was involved either as main or supplementary caregiver compared to when the parent was not involved. Thus it seems that based on the views of the key informants, AIDS caregiving is more likely to be stressful or create burdens for parents who care for children, especially when involved as a main care provider, than when others shoulder the major responsibility.

Table 8. Percentage of adults currently ill with or who died of AIDS for whom caregiving was a burden for the caregiver by role of parents in caregiving

	All cases	Parent was a main caregiver	Parent helped with caregiving	Parents dead or not involved with caregiving
% for whom caregiving was a serious burden overall	78.8	87.3	64.9	70.4
% for whom the following specific types of burdens were mentioned				
physical strain	36.8	44.0	27.8	28.4
emotional strain	42.2	51.8	30.6	30.9
financial strain	40.7	44.7	44.4	32.1
time strain				
(constant care needed)	32.9	40.4	19.4	25.9
other	9.6	11.4	5.6	9.9
N of cases	258-260	141-142	36-37	81

Note: Results are based on the subset of cases for whom supplemental information was collected and exclude cases for whom there was no caretaker.

Expenditures Associated with Treatment

Several supplementary questions dealt with expenditures associated with treatment and care of persons with AIDS. Key informants were asked if the expenditures were substantial, who paid for the expenses, and if the expenses were a burden for the family of the person with AIDS. Table 9 indicates the extent to which the expenses were considered substantial and the extent to which they were a burden to the family. The percent for whom expenses were judged to be substantial declines with the recency of the year of death, especially for most recent deaths. As the results reveal, the main reason for the decline in expenses is the increase in cases for whom insurance covered the costs. Based on our conversations with the informants, the insurance referred to was in most cases in the form of a household health card that can be purchased for a modest annual fee from the public health system. The card entitles up to 5 members of a household to free health services at government facilities and covers normal medications prescribed as part of treatments. In a few cases, insurance was provided free as a welfare measure to indigent households and entitled members to similar benefits as the health card system. Neither type of insurance, however, covered the expensive retroviral treatments that have proven effective in the West.

Table 9. Percent distributions of adults who died of AIDS according to expense of treatment and extent to which treatment expenses were a burden to the family

	Total expenses for treatment were					Extent treatment expenses were a burden to the family				
	Substantial	Modest, little treatment received	Modest, insurance covered most costs	Total		Serious burden	Moderate burden	Little or not at all	Total	
				%	N				%	N
Total	40.1	15.1	44.8	100	252	38.1	31.0	31.0	100	239
Year of death										
Prior to 1996	50.0	12.5	37.5	100	24	48.0	28.0	24.0	100	25
1996-1997	48.4	14.0	37.6	100	93	36.8	34.7	28.4	100	95
1998-1999	32.1	15.2	52.7	100	112	37.1	27.6	35.3	100	116
Location										
Rural	42.0	17.2	40.8	100	157	37.7	33.3	29.0	100	162
Urban/peri-urban	36.0	10.7	53.3	100	75	39.0	26.0	35.1	100	77
Economic status of PDA (prior to illness)										
Good	65.8	5.3	28.9	100	38	19.0	38.1	42.9	100	42
Average	35.8	15.1	49.1	100	106	33.9	34.9	31.2	100	109
Poor	33.3	20.0	46.7	100	75	57.3	21.3	21.3	100	75
Economic status of parents (prior to child's illness)										
Good	48.6	8.1	43.2	100	37	16.7	33.3	50.0	100	42
Average	40.2	17.2	42.5	100	87	35.6	35.6	28.7	100	87
Poor	33.3	20.4	46.3	100	54	63.6	20.0	16.4	100	55

Notes: Results are based on the subset of cases for whom supplemental information was collected. PDA = Person who died of AIDS.

A higher percentage of rural than urban and peri-urban cases were judged more frequently to have substantial expenses although rural cases also were more likely to have modest expenses or little treatment. The economic status of the person who died of AIDS and of their parents prior to the illness are positively associated with the percent judged to have incurred substantial expenses but negatively related to the extent the expenses were judged to be a burden on the family. For example, almost two thirds of families of persons of good economic status who died of AIDS (66 percent) are reported to have had substantial expenses for treatment but this was said to be a serious burden for only a little less than a fifth (19 percent). In contrast, only one-third of families of persons of poor economic status are reported to have had substantial expenses but the expenses they had were a judged to be a serious burden for about twice as many (57 percent). Thus, in general, the better off the person who died or the better off their parents are, the more substantial were the expenses of treatment but the less likely the expenses were a burden to the family. This suggests the amount spent for treatment is in part a function of the ability to pay. Although the poor families spent less, the expenditures were more of a burden for them because of their more limited financial resources.

Table 10 provides information on who mainly covered the out-of-pocket costs of treatment for adults who died of AIDS. Informants were permitted to mention more than one type of person responsible for paying and did so in 20% of the cases. Thus the categories in the table include combinations of more than one main source, with any combination which included parents constituting its own category. In a small proportion of cases, there were virtually no costs involved either because the person who died went untreated or had all costs covered by insurance. Overall, in about a fourth of the cases, the person who died of AIDS and/or his or her spouse covered the costs. In slightly over two fifths of the cases, however, the parents of the person who died paid either by themselves or in combination with others. When results are conditioned on having a living parent, parents were involved as main sources of payment for treatment in over half of the cases. Moreover, the role of parents in covering expenses varied with the living arrangements of the adult child who died. Parents were a main sources of payment for 6 out of 10 cases where the child lived with the parents during the illness, in about 4 out of 10 cases when the child lived adjacently, and only a little over a fourth of cases where the child lived elsewhere.

Table 10. Percent distribution of main persons paying for out of pocket treatment expenses for adults who died of AIDS, by residence in relation to parent(s) at time of terminal stage of illness

Main person(s) paying treatment expenses	All cases (including parents not alive)	Cases with a parent alive at time of illness			
		All cases with a parent alive	Lived with parents when ill	Lived next to parent when ill	Lived elsewhere when ill
Self and/or spouse only	25.3	23.6	20.1	36.4	29.7
Parent(s) only	31.0	37.4	45.8	27.3	10.8
Parent(s) and others(a)	11.8	14.3	13.9	13.6	16.2
Other (a)	25.3	18.7	13.2	22.7	37.8
No expenses	6.5	5.9	6.9	0.0	5.4
Total percent	100	100	100	100	100
Number of cases	245	203	144	22	37

Note: Results are based on the subset of cases for whom supplemental information was collected.

(a) Includes combinations with self and or spouse.

Table 11 shows the percentages for whom the expenses were judged to be substantial and to be a burden to the family according to who was the main source paying for treatment. The extent to which payments were judged to be substantial was highest when parents joined with others to cover treatment expenses but in cases where parents were the only persons responsible, a more moderate percentage is cited as having substantial outlays. This may in part reflect a tendency for family members to pool resources when higher expenses were involved. However, expenses were judged to be a burden for higher percentages of both cases in which parents were the sole main source of payment and where parents joined with others to pay compared to other situations.

Table 11. Percentage for whom expenses for treatment were substantial and percentage for whom expenses for treatment were a burden for the family by main persons paying for treatment expenses for adults who died of AIDS

Main person(s) paying treatment expenses	% for whom expenses were substantial		% for whom expenses were a serious burden to family	
	%	N	%	N
Self and/or spouse only	48.1	54	32.8	58
Parent(s) only	39.4	71	42.5	73
Parent(s) and others(a)	55.6	27	44.4	27
Other only(a)	32.2	59	36.7	60

Note: Results are based on the subset of cases for whom supplemental information was collected.

(a) Includes combinations with self and or spouse.

The results regarding expenditures indicate that, in the view of key informants, expenses incurred for treatment persons who died of AIDS are substantial for a sizeable minority (40 percent) of cases. That it is not higher appears to be largely because costs of treatment are often covered to a substantial extent by some form of government health insurance. Likewise, the expenses incurred create a serious burden for a similar proportion (38 percent). There is only an imperfect association, however, between how substantial expenses were and whether they were a serious burden. Thus while for cases where expenses were judged to be substantial, about half were also judged to be a serious burden, expenses were also judged to be a serious burden for a third of the remaining cases. This reflects the fact that the extent to which expenses are a burden is a function both of the amount spent and the financial status of those who pay. Since those who are better off also tend to pay more, substantial expenses do not always create a financial burden. At the same time, moderate expenses for a poor family can be quite consequential.

Economic Consequences

The illness and death from AIDS of a family member can impact the family economically in numerous ways. As shown above, covering the costs of treatment and caretaking expenses was judged to be a serious burden for the family in a sizeable minority of cases and at least a moderate burden in a substantial majority of cases. Meeting these expenses as well as funeral expenses could lead to the sale of property or major possessions, could lead a family into debt, or could result in one or more family members taking on additional work to earn extra income to cover these expenses. Caregiving responsibilities could also have substantial opportunity costs associated with them if the time that was devoted to caring for the ill family member would otherwise have been used for income generating or other activities of value to the caregiver.

We asked the key informants about each of these issues. The results are summarized in Table 12. For most issues, we did not directly ask if the impact was felt specifically by the parents of the AIDS case. Obviously parents can only be impacted if they were alive at the time of the adult child's illness. In addition, they are undoubtedly more likely to be impacted in many of the ways examined if the ill child coresided with them. For these reasons, besides showing results for all cases who died of AIDS, we also condition results on those cases that had a living parent, and further on those who coresided with a parent during the time of illness.

Table 12. Percentages of families of adults who died of AIDS who experienced selected consequences

Consequence	All persons who died of AIDS		Persons with a living parents		Persons who died of AIDS and lived with parent when ill	
	%	N	%	N	%	N
% whose family sold property or possessions	11.2	206	11.7	171	10.4	125
% whose family went into debt	12.1	206	14.0	171	14.4	125
% whose family sold property or possessions or went into debt	23.3	206	25.7	171	24.8	125
% for whom a family member had to reduce or stop working	33.3	248	35.8	204	38.5	143
% for whom a parent had to reduce or stop working	16.5	248	19.6	204	25.9	143
% for whom a family member had to increase work to earn extra income to cover expenses	11.6	242	12.6	199	12.1	141
% for whom a parent had to increase work to earn extra income to cover expenses	3.3	242	4.0	199	5.0	141

Note: Results are based on the subset of cases for whom supplemental information was collected.

Overall, 11 percent of families are reported to have sold property or possessions as a result of a member dying of AIDS and another 12 percent went into debt by borrowing money. Thus almost a fourth of all cases either sold property or possessions or went into debt as a result of treatment expenses. Results are fairly similar when conditioned on cases with a living parent or cases who coresided when ill. In a third of all cases of an adult dying of AIDS a family member is reported to have reduced time devoted to work or to have stopped working all together for some period of time. We also asked who the persons were who stopped or reduced work and thus for this measure we are able to determine directly if a parent was so affected. Overall, in about half of the cases where work was stopped or reduced, a parent was involved. When results are conditioned on having a living parent or coresiding when ill, the percentages for whom a family member reduced or stopped working increases as does the percent of cases in which a parent had to stop working. Fully a fourth of coresident cases involved a parent taking time away for work to care for the sick child. It thus appears that in a substantial minority of cases opportunity costs were incurred because of forgone income from work that otherwise would have been done. In many cases this stoppage affected parents directly.

The proportion of cases in which a family member increased work to earn extra money to cover the costs associated with a family member with AIDS is fairly modest and less than that of taking time from work. For all cases, as well as for those conditioned on having a living parent or coresiding with a parent, about one in eight involved someone taking on additional work. The person to take on extra work was usually someone other than a parent. Thus even in coresident cases, only 5 percent of cases are reported to have caused a parent to take on extra income earning activities.

Table 13 provides information on how economic consequences are related to the economic status of the parents prior to the child becoming ill for cases who died of AIDS and had a living parent as well as those who were coresident with a parent while ill. Two measures are shown. One is the percentage of cases in which property or possessions were sold or the family incurred debt to cover the costs associated with the person who died of AIDS. As noted above, this does not necessarily mean that parents were the ones who sold property or incurred debt but this was probably so in many of the cases, particularly when the child was coresident when ill. The other measure is based on a direct question about the parents and indicates the percentage of cases for whom the key informant judged that the parents' economic situation noticeably worsened as a result of their child having AIDS.

A clear negative association is evident for both measures in relation to the economic status of the parents. In cases where the parents were of good economic status prior to the illness, only a very small percent of families had to sell property or possessions or go into debt compared to half or more of the cases with poor parents. Likewise the economic situation of parents whose economic status was good before their child was ill was much less frequently judged to have worsened than for cases of parents who were poor. At the same time, it is noteworthy that overall in only about a fifth of the cases was the parents' economic situation judged to have been noticeably worsened. For poor parents, however, the economic situation was said to have worsened for almost a third of the cases with a living parent and almost two fifths of the cases (38 percent) for cases who lived with parents when ill.

Table 13. Percentages of families of adults who died of AIDS who experienced selected consequences, by economic status of parents

	Total (a)	Economic status of parents (prior to child's illness)		
		Good	Average	Poor
<u>Persons with a living parent</u>				
% whose family sold property or possessions or went into debt	25.7	5.4	21.0	55.0
N of cases	171	37	81	40
% whose parents economic situation noticeably worsened	19.6	6.7	19.6	31.4
N of cases	212	45	92	51
<u>Persons who lived with parent when ill</u>				
% whose family sold property or possessions or went into debt	24.4	4.4	21.2	50.0
N of cases	125	23	66	30
% whose parents economic situation noticeably worsened	22.9	7.1	20.6	37.8
N of cases	150	28	73	37

Notes: Results are based on the subset of cases for whom supplemental information was collected.

(a) includes a small number of cases with unknown economic status.

Another way in which the AIDS epidemic can impact on parents economically is through the loss of financial support from a child that becomes ill and dies. As noted earlier, financial and material assistance from adult children constitute an important element of the pervasive informal support system for older persons in Thailand. Thus the loss of an adult child can mean the loss of current or future support or both. We did not ask the key informants about their opinion as to the extent of loss of future support that would be forthcoming had the child not contracted AIDS since it would be very difficult from them to reliably assess this. Some indication of the importance for the loss of current support can, however, be gleaned from the information they provided in response to a question about whether the person with AIDS was the main income earner of the family before becoming ill. Assessing the relevance of the answers for the parents is complicated by the fact that the question referred to "family" rather than specifically to parents. Adult children who are reported not to be the main earners can be ruled out as main supporters of their parents. Ambiguity arises, however, for those who are reported to be main earners since the family that they are supporting may not include their parents. Nevertheless, combining the information about being a main income earner with information about residence before becoming ill and marital status can shed some light on this issue.

Among adult children who are reported to be main earners for their family, those who were coresiding with parents before becoming ill are more likely to be the parents' main source of support than those living outside the household. It is important to consider where the child resided before becoming ill rather than afterwards since presumably few of the adult children who returned to their parental home after becoming ill would have been in a position to take on the responsibility of providing for the household. Table 14 shows where adults who were ill with or died of AIDS lived before becoming ill. About a third lived with parents, a little over half had a living parent but did not live with him/her, and the remainder had no living parent. Marital status is clearly associated with residence before becoming ill.⁹ Single adult children were most likely and currently married children least likely to be living with parents. Those who were formerly married were most likely not to have a living parent, reflecting their older average age compared to single and currently married children (see Table 5).

Table 14. Percent distribution of adults currently ill with AIDS or who died of AIDS according to residence in relation to parent(s) prior to becoming ill, by marital status

Residence prior to becoming ill with AIDS	All cases	Marital status (a)		
		Single	Currently married	Formerly married
With parents	33.2	46.8	26.0	31.9
Not with parents but parent(s) were alive	53.6	45.5	61.1	48.6
No parent alive at time when illness began	13.2	7.8	13.0	19.4
Total percent	100	100	100	100
Number of cases	280	77	131	72

Notes: Results are based on the subset of cases for whom supplemental information was collected.

(a) For persons who died of AIDS, marital status refers to the marital status at the time of death.

Table 15 shows the percent distribution of parents of adult children currently ill with AIDS or who died of AIDS according to a hierarchy of situations intended to approximate the likelihood that the child was the primary source of support for the

⁹ Since marital status reflects each person's situation at the time of illness or death, it may be different from marital status before becoming ill. However, the two are likely to largely be the same, especially with respect to being single or ever married, as it seems unlikely many persons would have married after becoming ill. However, some formerly married persons may have been married at the time they became ill. In some cases the illness may have led to marital dissolution or to spousal death, if the spouse was also infected.

parents.¹⁰ The categories are based on the marital status and place of residence prior to illness of the adult child, in addition to the status as a main income earner for the family.

Table 15. Percent distribution of parents of adults currently ill with AIDS or who died of AIDS according to a combined measure of marital status, coresidence status prior to illness, and main provider status of the adult child, by sex and by age of the parent.

Marital status, coresidence status before illness, and main earner status of adult child	All parents	Sex of parent		Age of parent	
		Father	Mother	under 60	60+
1. Single, coresident & main earner	6.3	5.0	7.3	7.7	6.4
2. Ever married, coresident & main earner	10.3	10.6	10.0	6.0	17.8
3. Single, not coresident & main earner	4.5	5.6	3.7	5.5	3.2
4. Ever married, not coresident & main earner	29.7	30.4	29.2	24.2	28.0
5. Not a main earner	49.2	48.4	49.8	56.6	44.6
Total percent	100	100	100	100	100
N of cases	380	161	219	182	157

Note: Results are based on the subset of cases for whom supplemental information was collected.

The most likely cases to have been the main source of support for parents are coresident single children who are reported to have been the main income earner. For most or even all of these cases, the ‘family’ being supported would either be or include parents. Coresident ever-married children who are described as main income earners are also likely to have been the primary support for parents, although it is possible that the family to which the key informant referred was limited to their spouse and/or children rather than all members of the household. The family for whom non-coresident single children who are reported to have been main income earners is likely to refer to parents. They are likely providing income for their parents through remittances.¹¹ Ever married non-coresident children who are reported as main income earners, however, are considerably less likely to have been the primary source of support for their parents. Presumably the family for which they were primarily responsible refers to their spouse and/or children.

¹⁰ In the small percent of cases where parents were not living together at the time of their child’s death, we did not ascertain with which parent the child resided. In these cases we attribute coresidence to both parents although presumably it would be the actual case for only one. Thus we tend to slightly overstate the proportions of parents that are in the first two categories of the hierarchy.

¹¹ A small number of cases in regards to the question of being the main income earner for the family were coded as “living alone”. These have been coded as not being a main income earner for the family.

However, they may also have provided important support through remittances that could have been the parents' main support.¹²

Finally, regardless of their marital status or household of residence, adult children who were reported as not being main providers for their families obviously were not primary sources of support for parents although they still may have provided some financial or material assistance of secondary importance.

The results in Table 15 indicate that, for about half of the parents who had a an adult child with AIDS, the child was not the main family income earner (the last category in the table) and thus clearly not the primary source of support for the parent. For another 30 percent of parents, the child with AIDS, although being described as the main family income earner, was either currently or formerly married and not coresident before being ill (the fourth category in the table). Probably most of these non-coresident ever-married children were the primary source of support for their own conjugal families and not for their parents. For the remaining 21 percent of parents (constituting the first three categories in the table), the child with AIDS was likely to be their primary source of support. The actual proportion of parents for whom the child with AIDS was the main source of support could be somewhat higher than this. Such would be the case if the share of those in the fourth category who received primary support from the child exceed the share in the first three categories who did not. However, since most cases in the fourth category probably were not primarily supported by the child with AIDS, a maximum plausible estimate is unlikely to exceed 25 percent. Nevertheless, even if the true proportion of parents who lose their primary source of support as a results of AIDS is closer to a fifth than a fourth of all parents of adult children with AIDS, this is still a substantial proportion. Moreover, some additional share is losing a secondary source of support and in some cases this may have important implications for their financial well being. In addition, the ultimate impact of AIDS on support of parents needs to take into account the loss of future support that would have been provided had the child not gotten AIDS, an aspect for which our key informant data can not provide information.

Results in Table 15 are also shown by the sex and the age of the parent. In general, the distribution of children according to the hierarchy of situations being considered differs little between mothers and fathers. Some differences, however, are notable between

¹² That non-coresident children can be the main source of support for parents is evident from results of the nationally representative 1995 Survey of Welfare of Elderly in Thailand (SWET). According to SWET, almost a third (32 percent) of parents aged 50 and over who did not have any child coresiding reported that children were their main source of support (original tabulation). It is possible that the support referred to was the combined results of several children's contributions and that no individual child was the main source. The data in SWET do not permit determining if the support was the result of an individual child acting as the main contributor or if the support was a product of the contributions of more than one child, none of whom played a dominant role. Thus it can not be determined from SWET how frequently non-coresident married children were the main source of older parents support. The SWET results do show, however, that more than half (52 percent) of single non-coresident children and almost a third (32 percent) of ever married non-coresident children gave at least 1000 baht (about US \$40 at that time) parents age 50 and over during the prior year (original tabulations).

younger and older parents. Those who are age 60 or older are far more likely than parents who under 60 to have had a child with AIDS who had been married and was coresident and a main earner. Older parents were also substantially less likely to have had a child with AIDS who had not been reported as a main earner. It thus appears that older parents whose child had AIDS are more likely than younger parents to have lost a child who was providing primary support.

Care of AIDS Orphans

One consequence of the AIDS epidemic for family members that has received considerable attention both in Thailand and internationally is the need for caring for the dependent children of persons who die of AIDS (Boonchalaksi and Guest 1993; Brown and Sittitrai 1995; UNAIDS 1999). These children are commonly referred to as “AIDS orphans” even when one of their parents remains alive. Overall, 42 percent of the adults who died of AIDS had one or more dependent children. For the subset of cases about whom additional information was collected, if there were any dependent children, we asked who cared for them after the parent became ill or died. Table 16 indicates the fostering arrangements for the dependent children left behind by adults who died of AIDS. The percents sum to over 100 because in about 8 percent of the cases, the dependent children were cared for by different parties at different times. Since we are particularly interested in the role of older persons, and especially parents of the adult who died, results are shown separately conditioned on the person who died having a living parent.

Table 16. Foster care provided to dependent children of adults who died of AIDS

Relation of foster care parent to person who died of AIDS (PDA)	% of adults who died of AIDS (and who had dependent children) whose children were taken care of specific types of relatives	
	All persons who died of AIDS	Persons who died of AIDS and had a living parent
spouse of PDA	50.8	52.4
parent of PDA	31.1	36.2
parent-in-law of PDA	15.6	13.3
other (including non-relatives)	10.7	6.7
N of cases	122	105

Note: Results are based on the subset of cases for whom supplemental information was collected. Percents add to over 100 because for some cases more than one fostering arrangement occurred.

The most common person to take care of the dependent child of persons who died of AIDS is the person's spouse. In about half the cases, the spouse cared for the child. Parents and parents-in-law (i.e. the grand parents of the AIDS orphans), however, account for a substantial proportion as well. In over a third of cases where the adult who died had a living parent, the parent took care of the grandchild. Parents-in-law also played a role in a number of cases. These results, however, do not reflect the full extent that parents or parents-in-law of persons who die of AIDS are likely to be responsible for the grand children left behind. The percentage of cases in which the grand parents will eventually provide care is likely to be substantially higher than observed at the time of our research. The reason is that some significant proportion of surviving spouses of persons who died of AIDS (the most common care taker in the current results) of these dependent children are themselves infected by HIV and are thus likely to die before the dependent child grows up and grand parents are likely to take over the responsibility of caring for the orphans in many such cases.¹³

Community Reaction

AIDS is considered to be a stigmatized disease throughout much of the world (Leary and Schreindorfer 1998). Stigma may be directed not only at PWAs themselves but also extended to those closely associated them and especially to those who are providing personal care (Goffman 1963; Powell-Cope and Brown 1992). Main manifestations of stigma include negative attitudes towards and disassociation with those who are stigmatized. Fear of negative reaction may prevent or postpone the return of a person ill

¹³ The likelihood that parents will take over responsibility is strongly suggested by the finding that parents of the person who died of AIDS provided care to the orphaned grandchildren in 74 percent of the 19 cases in which the person who died of AIDS was widowed, had a dependent child, and had a living parent. This is substantially above the 52 percent shown in Table 16 for persons of all marital statuses who died of AIDS and had a living parent.

with AIDS to their home community or may lead some to leave their home to go to a locality where they can have greater anonymity or receive more support (Brown and Sankar 1998; Sankar et al. 1998). Stigma associated with AIDS can thus be a hindrance to caregivers and can complicate interaction between informal caregiving and seeking services from the public or private health system or social services by PWAs or their family members (Ory, Zablotzky and Crystal 1998b). At the same time, the nature, degree, and consequences of stigma are likely to vary considerably across settings and over time.

In the key informant interviews, we collected information about community reaction to persons with AIDS and their families in two different ways. We first asked key informants about their general impression of the local community reaction to families with a member who has AIDS and whether the reaction has changed over time (see Appendix A, questions 4 and 5). We also asked for case-specific information for the subset of cases for whom we collected supplementary information. For these cases we asked how open the family was about a member having AIDS as well as how the community reacted to the family both during the time of illness and after the death of the person with AIDS (see Appendix C, questions 2-6). In interpreting the results, it is important to consider that the key informants were mainly staff of the public health system whose assignments include, among many other matters, helping educate the public about AIDS and promoting a public climate that does not unduly stigmatize AIDS inflicted persons out of unfounded fears of risks they pose. Thus their responses may be more sanguine than had the families of the AIDS afflicted persons been asked themselves.

For most (71 percent) of the 77 sites for which we asked a generalized opinion, the key informants described most community members as being not especially concerned (indifferent) about families in which a member has AIDS. In only a small minority of sites (12 percent) was the predominant reaction described as avoidance and/or criticism. In almost as many sites (10 percent) the predominant reaction was described as showing sympathy. Less clear characterizations were given in the few remaining sites.

The characterizations of community reaction to families with a member with AIDS differed somewhat by region. In particular, in the 14 sites included in the two upper northern provinces (Chiang Mai and Chiang Rai), where prevalence is highest and AIDS has been at a substantial level longer, the percent with predominately sympathetic reactions was higher than elsewhere (21 percent versus 8 percent). Although many key informants reported that early in the epidemic there was considerable fear of associating with AIDS cases, for the large majority (87 percent) of sites throughout the country and in every upper northern site, community reaction was reported to have improved over the course of the epidemic.

Table 17 shows the percentage of families of persons who died of AIDS who were reported to be generally open with other community members about the nature of the illness. The question soliciting this information did not specify at what point the family became open. Thus some may have been open about a member having AIDS from the early stages of the illness, while others may have admitted it only after the person died.

The question about family openness also did not refer specifically to parents and thus the results cannot be directly interpreted to refer to any particular family members. Given our interest in the impacts of the epidemic on older persons, and particularly on the parents of adults with AIDS, Table 17 and 18 (which refers to negative community reaction) show results for (a) all cases who died of AIDS and (b) cases conditioned on those who lived with the parents when ill. For this latter group, the chances that the responses encompass characterizations that include or refer to the parents would logically seem to be higher than for the full set of cases (which include cases for whom the parents were dead or lived separate from the person with AIDS during the illness).

Table 17. Families of persons who died of AIDS that were open with community members about the nature of the illness

	All persons who died of AIDS		Persons who died of AIDS and lived with parent when ill	
	% generally open	N of cases	% generally open	N of cases
Total	58.3	252	58.5	147
Year of death				
Prior to 1996	57.1	28	50.0	12
1996-1997	57.8	102	56.4	55
1998-1999	58.8	119	61.5	78
Region				
Upper north	77.5	80	78.3	46
Elsewhere	49.4	172	49.5	101
Location				
Rural	60.5	172	60.6	104
Urban/peri-urban	53.8	80	53.5	43
Sex of PDA				
Men	56.7	187	58.9	107
Women	63.1	65	57.5	40
Marital status of PDA				
Single	58.5	65	53.7	54
Currently married	56.5	124	58.2	55
Formerly married	61.9	63	65.8	38
Economic status of PDA (prior to illness)				
Good	48.9	45	46.2	26
Average	55.7	115	59.2	76
Poor	65.4	78	65.0	40
Economic status of parents (prior to child's illness)				
Good	42.2	45	50.0	28
Average	57.4	94	57.5	73
Poor	67.3	55	69.2	39

Notes: Results are based on the subset of cases for whom supplemental information was collected.

PDA = Person who died of AIDS

The results show that almost 6 out of 10 families of all persons who died of AIDS were thought to be open about the nature of the illness, which is nearly identical to the proportion of those cases where the person lived with parents while ill. In general, the relationship between openness and the selected covariates shown in the table are quite similar for this subset and for the whole sample. One exception is with respect to year of death. Overall there appears to be little relation with the year of death while for cases who lived with parents the percent who were open increases somewhat over time. A pronounced difference in openness is associated with region. Families in the two upper northern provinces were far more likely to be open than elsewhere. Rural families are also reported to be more open, perhaps because there is less anonymity in rural than urban settings, and because higher proportions of a rural than an urban community typically attend a funeral. Both of these presumed differences would make it more difficult for rural families to hide the cause of illness and death. A modestly higher percent of openness is reported for families of women who died than of men in the entire sample, but little difference in the subset who lived with parents. Marital status of the person who died shows some association with openness, being least frequent for single persons and most common for formerly married ones. More pronounced is the negative association between openness and the economic status of either the person who died or their parents. Being better off decreases the probability of being open.

Table 18 shows the percentage of cases for which the key informant reported some negative community reaction toward the family of persons who died of AIDS during the time of the illness and after the death. We focus on negative reactions since most of the concern about community reaction to the AIDS epidemic focuses on stigma and not on positive reactions. We note, however, that the most commonly reported reaction is a basically neutral one (for 38 percent of cases during illness and 80 percent following death) and that community reaction was reported to be positive, either in terms of being sympathetic or even by providing assistance, for a notable minority of cases (for 35 percent of cases during illness and 11 percent following death).

Negative community reaction to the family during the time of illness was reported for 28 percent of cases overall but for only 22 percent of cases who lived with a parent when ill. Following the death of the person with AIDS, less than 1 in 10 families are reported to have experienced negative community reaction. Negative reactions were reported for higher proportions of early cases of AIDS (pre-1996) than more recent ones both during the illness and following the death. Likewise, in both situations, negative reactions are reported noticeably less for families of cases in the upper north compared to elsewhere in Thailand and for rural than for urban/peri-urban families. The sex of the person with AIDS shows little association with negative community reaction. During illness, marital status of the PWA is associated in the overall sample with negative reaction (lowest if single and highest if previously married) but not for the subset who lived with a parent while ill. Economic status of the PWA and of the parents is associated with negative reaction to families during illness. Well off suffer less negative reaction generally. Poor economic status of the PWA is associated with more negative reaction compared to

average or good economic status. In some contrast, better economic status of the parents is distinctively associated with lower negative reaction compared to both average and poor status.

Table 18. Families of persons who died of AIDS that experienced negative community reaction

	During Illness of PDA				After death of PDA			
	Families of all cases		Families of cases who lived with parent when ill		Families of all cases		Families of cases who lived with parent when ill	
	%	N	%	N	%	N	%	N
Total	28.4	204	22.0	127	8.6	210	7.9	126
Year of death								
Prior to 1996	59.1	22	40.0	10	20.8	24	18.2	11
1996-1997	28.1	82	20.8	48	4.7	85	4.4	45
1998-1999	21.4	98	20.6	68	8.2	98	7.4	68
Region								
Upper north	20.0	80	6.4	47	2.6	78	2.2	45
Elsewhere	33.9	122	31.3	80	12.1	132	11.1	81
Location								
Rural	27.1	144	20.4	93	5.6	144	3.3	90
Urban/peri-urban	31.7	60	26.5	34	15.2	66	19.4	36
Sex of PDA								
Men	29.6	152	22.1	95	7.7	155	8.6	93
Women	25.0	52	21.9	32	10.9	55	6.1	33
Marital status of PDA								
Single	23.2	56	21.3	47	6.9	58	8.2	49
Currently married	31.3	96	22.0	50	9.2	98	6.4	47
Formerly married	38.9	52	23.3	30	9.3	54	10.0	30
Economic status of PDA (prior to illness)								
Good	22.2	36	13.0	23	2.9	35	0.0	21
Average	24.7	89	21.9	64	11.1	99	10.1	69
Poor	37.3	67	28.7	35	9.4	64	9.7	31
Economic status of parents (prior to child's illness)								
Good	11.4	35	7.7	26	5.6	36	0.0	26
Average	28.0	75	26.7	60	10.0	80	11.3	62
Poor	27.3	44	23.5	34	9.5	42	9.7	31

Notes: Results are based on the subset of cases for whom supplemental information was collected.
PDA = Person who died of AIDS

Discussion

Information solicited from key informants on individual cases of persons who died of AIDS or were currently living in the community with symptoms provides the basis for the present study. The data provide a quantitative assessment of the impact of the AIDS epidemic in Thailand on older persons, particularly parents of adult AIDS cases. As discussed above, the key informant approach provides an innovative and efficient way to gather such data indirectly and thus avoids the problems of locating, soliciting cooperation from, and burdening a representative sample of affected persons and directly asking them questions that are likely to deal with matters that are very sensitive for them. At the same time, obtaining such information indirectly poses its own risks and potential biases or inaccuracies created by incomplete knowledge that need to be acknowledged when interpreting the results. The accuracy of the information provided is also likely to vary with the particular subject matter being addressed. Straight forward and more readily observable information on whether the person with AIDS lived with his or her parent when ill and whether the parents participated in care taking may well be easier for a key informant to provide than more complicated issues about the amounts of a family's expenditures on the illness, how they financed them and what the economic repercussions for the family were. In recognition of this, we limited our collection of what we expected to be questions requiring better knowledge of the situation to cases that the informant knew best. Even so, this still does not ensure that the key informant had full and accurate knowledge of each case reported. Nevertheless, we believe the data provide the basis for a useful contribution to documenting an important but largely overlooked aspect of the AIDS epidemic.¹⁴

The information provided by the key informants shows unequivocally that the AIDS epidemic in Thailand has an extensive impact on older people through their involvement in the living and caretaking arrangements of their infected adult children. Two-thirds of adults who died of AIDS lived with or next to a parent by the terminal stage of illness and a parent, usually the mother, acted as the main caregiver for about half. Moreover, for 70 percent of our cases, a parent or other older generation relative provided at least some care. The vast majority of these parents and relatives were age 50 or more and many were in their 60s and even 70s.

Parents often also cover some or most of the expenses associated with the illness. For 43 percent of all cases reported, parents played a main role (sometimes assisted by others) in paying for treatments. For cases who had a parent alive at the time of illness, the percentage reaches over half (53 percent). While parents were more likely to bear or share the main responsibility for treatment costs when their ill child lived with them, they still took on this responsibility in over a fourth of the cases where the child neither lived

¹⁴ The project of which this study is one part also includes a survey in which a sizeable sample of parents of adults who died of AIDS have been interviewed. Once results of this survey become available, we can cross-check results.

with nor adjacent to them. At the same time, the expenses for treatment were not always judged to be substantial nor were they necessarily a serious burden for the parents. The key informants reported that in only two fifths of all cases were expenses substantial and in almost as many were they a serious financial burden for the persons paying. For those cases where parents were a main source of payment, the percentages were only modestly higher. In about a forth of the cases, the family was reported to have either sold property or possessions or to have gone into debt to cover expenses associated with the PWA.

An important moderating influence on the financial impact of AIDS treatment on the families of PWAs is the wide availability of basic government health insurance which many use to cover most treatment. Such insurance does not cover expensive anti-retroviral treatments that are proving effective in prolonging the lives of HIV infected persons in the US and other economically advanced countries as these are not widely available in Thailand generally and thus in practice can not yet be considered viable treatment options for most families.

There were other ways besides paying for treatment that family members including parents could be negatively impacted economically. Caregiving involves opportunity costs. According to the key informants, in a third of the cases, some family member reduced or stopped working to provide care and in a sixth of the cases a parent did so. For only very few cases was it reported that someone had to take on additional work to cover expenses. Even more rarely was this a parent. Based on indirect evidence, it appears that for at least a fifth and perhaps as much as a fourth of the parents of adult children with AIDS, the child was the main income earner for the parental household. The death of the child also removes the potential support he or she would have provided to the parents in their old age. However, since most of the parents of adults dying of AIDS at present went through their reproductive years when fertility levels were still at least moderately high in Thailand, the large majority have other children on whom they can eventually depend.¹⁵ Inheriting responsibility for bringing up dependent children of the person has more immediate economic impact on persons whose adult child died. In about two fifths of the cases, the person who died had dependent children and in close to half of these cases either the parents or parents-in-law of the deceased were involved with raising these children.

Overall, the economic impact of the loss of a child to AIDS does not appear to be devastating for the parents in most cases, at least according to the reports of key informants. This is conveniently summarized in the responses given when asked if the economic situation of the parents noticeably worsened as a results of the loss of their child to AIDS. In only about 20 percent of the cases (with parents alive at the time the child died) was this reported to be the case. In part, this reflects the fact that of parents

¹⁵ According to the nationally representative 1995 Survey of Welfare of Elderly in Thailand, persons in their fifties averaged over four living children and persons 60 and over averaged over five. Among persons with at least one child, only 6 percent of those in their fifties and 5 percent of those 60 or over had only one child.

who spent substantial amounts on treatment, a disproportionate share were economically better off than average and hence could afford to without enduring undue financial hardship. Nevertheless, an important qualification to this picture of modest levels of economic impact is that the poor appear to be the most adversely affected. Even if their expenses or other economic impacts were not large in absolute amounts, they could still be severely taxing relative to their resources. This is reflected in the fact that for poor families, treatment expenses were far more likely to be reported to be a serious burden, and for far higher proportions the economic situation of the parents was reported to have worsened.

The high level of parental involvement in the caregiving and living arrangements of adult children who become ill with AIDS contrasts sharply to the situation in the US (and probably other western countries). Several US studies indicate that caregivers are seldom age 50 or over and typically are not members of the PWA's family of origin but instead are commonly partners, lovers or friends (Turner et al. 1994; Turner et al. 1998).¹⁶ The Thai situation obviously has aspects that are unique to Thailand. Thus caution must be used in drawing inferences for other countries. Yet in important ways there are broad similarities with many other settings in the developing world, especially when compared to the US or other economically advanced countries of the West. These include the predominance of heterosexual transmission of HIV, a social atmosphere tolerant of transactional sex, the lack of extensive formal support and services for persons suffering with AIDS, and primary reliance on exchanges between parents and adult children for old age support including extensive coresidence. We thus expect that the involvement of older persons in the living and caretaking arrangements of persons with AIDS in many other developing countries will be far closer to that revealed for Thailand than typical of the US situation. At least one recent study in Uganda confirms the primacy of parents as caregivers to adults with AIDS (Ntozi and Nakayiwa 1999). Clearly more attention needs to be given to assessing the extent and nature of how the AIDS epidemic impacts older populations not just in Thailand but elsewhere in the developing world as well as to the public health and social service implications of those impacts for the older persons who are affected.

¹⁶ We speculate elsewhere in some detail about the reasons underlying the different level of involvement of parents in Thailand and the US (Knodel et al. forthcoming-b).

References

- Allers C.T. (1990) AIDS and the older adult. *The Gerontologist* 30(3):405-7.
- Boonchalaksi, W. and Guest P. (1993) AIDS and Children: Prospects for the year 2000. IPSR Publication No. 168, Institute for Population and Social Research, Mahidol University, Thailand.
- Brabant S. (1994) An overlooked AIDS affected population: the elderly parent as caregiver. *Journal of Gerontological Social Work* 22(1-2):131-45.
- Brown D.R. and Sankar A. (1998) HIV/AIDS and aging minority populations. *Research on Aging* 20(6):865-884.
- Brown T. and Sittitrai W. (1995) The Impact of HIV on Children in Thailand. Program on AIDS, Thai Red Cross Society, Research Report No. 16 (June 1995).
- Brown T. and Sittitrai W. (1995) Heterosexual risk behaviour in Asia: the implications for HIV/AIDS. *Current Science* 69(10)(25 November 1995): 840-848.
- Brown T., Sittitrai W., Vanichseni S. and Thisyakorn U. (1994) The recent epidemiology of HIV and AIDS in Thailand. *AIDS* 1994, 8 (supplement 2): S131-S141.
- Brown T. and Xenos P. (1994) AIDS in Asia: The Gathering Storm. *Asia Pacific Issues. Analysis from the East-West Center* No. 16, August 1994, 1-15.
- Crystal S. and Glick Schiller N. (1993) Stigma and homecoming: family caregiving and the "disaffiliated" intravenous drug user. In: Zimmerman R. and Albrecht G. (eds.) *Advances in Medical Sociology*, vol. 3, pp. 165-184. JAI, Greenwich, CT.
- Ellis M. and Muschkin C. (1996) Migration of persons with AIDS--a search for support from elderly parents? *Social Science & Medicine* 43(7):1109-18.
- Ford N. and Koetsawang S. (1991) The social-cultural context of the transmission of HIV in Thailand. *Social Science and Medicine* 33 (4): 405-414.
- Goffman E. (1963) *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs, NJ: Prentice Hall.
- Im-em W. (1999) Mortality Trends and Levels to Verify the AIDS Epidemic in Thailand: Analysis from Death registration Statistics, 1984-1997. ISPR Publication 239. Bangkok: Institute for Population and Social Research, Mahidol University.
- Knodel J., Chayovan N., Graiurapong S. and Suraratdecha C. (Forthcoming-a) Ageing in Thailand: an overview of formal and informal support. In: Phillips D. (ed.) *Ageing in the Asia-Pacific Regions: Issues and Policies*. Routledge, London.

- Knodel J., Saengtienchai C. and Sittitrai W. 1995. "The Living Arrangements of Elderly in Thailand: Views of the Populace," *Journal of Cross-Cultural Gerontology* 10: 79-111. (April 1995).
- Knodel J., VanLandingham M., Saengtienchai C. and Im-em W., (Forthcoming-b) "Older People and AIDS: Quantitative Evidence of the Impact in Thailand," *Social Science and Medicine*.
- Knodel J. and Saengtienchai C. (1999) Studying living arrangements of the elderly: lessons from a quasi qualitative case study approach in Thailand, *Journal of Cross-Cultural Gerontology* 14(3): 197-220.
- Leary M. and Schreindorfer L. (1998) The stigmatization of AIDS: rubbing salt in the wound. Chapter 2 in Valerian Derlega and Anita Barbee (eds.) *HIV & Social Interaction*, pp.12-29. Thousand Oaks: Sage.
- LeBlanc A.J., London A.S. and Aneshensel C.S. (1997) The physical costs of AIDS caregiving. *Social Science & Medicine* 45(6):915-923.
- Levine-Perkell J. (1996) Caregiving issues. In: Nokes K.M. (ed.) *HIV/AIDS and the Older Adult*. Taylor & Frances, Bristol, PA.
- Levy J. and Albrecht G. (1989) Methodological considerations in research on sexual behavior and AIDS among older people. In: Riley M.W., Ory M.G. and Zablotsky D.(eds.) *AIDS in an Aging Society*, pp. 96-123. Springer, New York.
- MAP (Monitoring the AIDS Pandemic). (1998) *The Status and Trends of the HIV/AIDS Epidemics in the World*. Harvard School of Public Health, Francois-Xavier Bagnoud Center for Health and Human Rights, Boston.
- Mullan J.T. (1998) Aging and informal caregiving to people with HIV/AIDS. *Research on Aging* 20(6): 712-738.
- National Economic and Social Development Board (NESDB). (1994) *Projections for HIV/AIDS in Thailand: 1987-2020*. NESDB, Bangkok.
- National Statistical Office, Thailand. (No date) *Report of the 1994 Survey of Elderly in Thailand*. National Statistical Office, Bangkok.
- Nazon M. and Levine-Perkell J. (1996) AIDS and aging. *Journal of Gerontological Social Work* 25(1-2):21-31.
- Nokes K.M. (ed.) (1996) *HIV/AIDS and the Older Adult*. Taylor & Frances, Bristol, PA.

- Ntozi J. and Nakayiwa S. (1999) AIDS in Uganda: how has the household coped with the epidemic? In: Orubuloye I.O., Caldwell J.C. and Ntozi J. (eds.) *The Continuing HIV/AIDS Epidemic in Africa: Response and Coping Strategies*, pp. 155-180. Health Transition Centre, Australian National University, Canberra.
- Ory M.G. and Mack K. (1998) Middle-aged and older people with AIDS. *Research on Aging* 20(6):653-664.
- Ory M.G., Zablotsky D. and Crystal S. (eds.) (1998a) Special Issue: HIV/AIDS and Aging. *Research on Aging* 20(6).
- Ory M.G., Zablotsky D. and Crystal S. (1998b) HIV/AIDS and aging: identifying a prevention research and care agenda. *Research on Aging* 20(6):637-652.
- Phoolcharoen W., Ungchusak K., Sittitrai W. and Brown T. (1998) Thailand: lessons from a strong national response to HIV/AIDS, *AIDS* 1998, 12(suppl. B): S123-S135.
- Powell-Cope, G.M. and Brown M.A. (1992) Going public as an AIDS family caregiver. *Social Science & Medicine* 34(5):571-580.
- Riley M.W., Ory M.G. and Zablotsky D. (eds.) (1989) *AIDS in an Aging Society*. Springer, New York.
- Sankar A., Luborsky M., Rwabuhemba T. and Songwathana P. (1998) Comparative perspectives on living with HIV/AIDS in late life. *Research on Aging* 20(6): 885-911.
- Spira A.N., Giami J.A. and Micheals S. (1998) Cross-national comparisons of sexual behavior surveys: methodological difficulties and lessons for prevention. *American Journal of Public Health* 88(5):730-32.
- Turner H.A. and Catania J.A. (1997) Informal caregiving to persons with AIDS in the United States: caregiver burden among central cities residents eighteen to forty-nine years old. *American Journal of Community Psychology* 25(1):35-59.
- Turner H.A., Catania J.A. and Gagnon J. (1994) The prevalence of informal caregiving to persons with AIDS in the United States: caregiver characteristics and their implications. *Social Science & Medicine* 38(11):1543-52.
- Turner H.A., Pearlin L.I. and Mullan J.T. (1998) Sources and determinants of social support for caregivers of persons with AIDS. *Journal of Health and Social Behavior* 39 (2):137-151.
- United Nations. (1999) *The Demographic Impact of AIDS* (ESA/P/WP.152). United Nations, New York.
- UNAIDS. (1998a) *Epidemiological Fact Sheet on HIV/AIDS and sexually transmitted diseases: Thailand*. UNAIDS, Geneva.

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

UNAIDS/WHO. (1998) *Report on the Global HIV/AIDS Epidemic, June 1998*. UNAIDS and WHO, Geneva.

UNAIDS (1999). *Children orphaned by AIDS: Front-line responses from eastern and southern Africa*. Geneva: UNAIDS.

van Griensven F., Surasiengsunk S. and Panza A. (1998) *The use of mortality statistics as a proxy indicator for the impact of the AIDS epidemic on the Thai population*. Publication No. 267/98. Institute of Population Studies, Chulalongkorn University, Bangkok.

VanLandingham M., Knodel J., Im-em W. and Saengtienchai C. (2000) The impacts of HIV/AIDS on older populations in developing countries: some observations based upon the Thai case. *Journal of Family Issues*. (Forthcoming Sept. 2000)

World Bank. (1994) *Averting the Old Age Crisis*. Oxford University Press, New York.

APPENDIX A
Key Informant General Information (Form KI-G)

Saw Aw ID _____

Introduction:

- 1) Introduce ourselves and give summary description of project to KI. Describe our study of AIDS and elderly and that we are collecting various types of data.
- 2) Explain purpose of visit - to collect information on PDA/PWAs and the role their parents played in their care. Explain KI are useful because sensitive nature of the information makes it difficult to contact OPAA directly.
- 3) Mention that we have two types of information we want:
 - a) basic data for all or most cases (form KI-G)
 - b) more detailed information on about 5-8 cases:
 - 3 cases of PDA/PWA 50+;
 - 5 cases of PDA/PWA under 50
- 4) Stress that we do not want to know the identify of cases.
- 5) Warn that we probably need several hours to complete the data collection and determine best time for this.
- 6) Ask if the KI has any questions about what we are doing.
- 7) Ask permission to tape record

Date of interview: _____ Day _____ Month _____ Year _____
 Interviewer: _____ Chanpen _____ Wassana _____ Other (specify) _____

Name of health station:

Village: _____ Tambol: _____
 Amphoe: _____ Changwat: _____

Key informants (including any supplementary ones not in health station):

Duration of employment at

	Name	Position	health station/in position
1.			
2.			
3.			
4.			

Other people present during interview:

___ JK ___ MVL ___ Other (Specify _____)

Number of villages in Tambol _____

Number of health stations serving Tambol (including this one) _____

Number of villages under health center responsibility _____

Number of households under health center responsibility _____

Year that the first AIDS case was found in the village _____

- 1) Is there a record of deaths (registry/listing/certificates) for the last few years available at health station?
 - ___ yes
 - ___ no (skip to next page)
 - ___ special AIDS death register
 - ___ other (specify _____)

- 2) How complete is the registry/listing of deaths?
 ____ appears complete or almost complete ____ incomplete
 ____ only for past year
 ____ only deaths at home
 ____ other (specify _____)
- 3) What is the source of information for the death registry that you keep? (Check all that apply)
 ____ VHV
 ____ family members/villagers report
 ____ funeral invitation
 ____ notifications from district
 ____ other (specify _____)
- 4) How would you describe the reaction of most people in the community to families that have some member get or die of AIDS? For example, are they indifferent, are they sympathetic, do they try to avoid them or what?
 ____ most indifferent
 ____ most avoid contact with family
 ____ most criticize family
 ____ most feel sympathy
 ____ KI does not have opinion
- 5) Has the community reaction changed much since the first case of AIDS appeared?
 ____ no
 ____ yes, became more tolerant or accepting
 ____ yes, became less tolerant or accepting
 ____ other (specify _____)
- 6) Are there any organizations that help PWAs or their families who live in the area that your health center covers?
 ____ No
 ____ Yes (List them: _____

 _____)
- 7) In total, how many died of AIDS since the epidemic started?
 Number _____ (____ exact count ____ rough estimate only)
- 8) In total, how many in total have symptomatic AIDS in your service area now?
 Number _____ (____ exact count ____ rough estimate only)
- 9) How many persons in your service area do you think are HIV+ but are not symptomatic?
 Number _____ (____ exact count ____ rough estimate only)
- 10) How many of the persons who died of AIDS, have AIDS or are HIV positive are age 50 or older?
 Number _____ (____ exact count ____ rough estimate only)

- 11) Are there cases of families in which more than one sibling died AIDS or contracted HIV?
____ No ____ Yes
(How many families? ____)
- 12) Excluding children and older persons over 50, about what proportion of all the deaths over the last 2-3 years would you say were due to AIDS?
- ____ 1 less than a third
 - ____ 2 a third or more but less than half
 - ____ 3 about half
 - ____ 4 more than half but less than two-thirds
 - ____ 5 two thirds or more

List AIDS deaths (up to 20) starting with the up to 3 cases of PDA aged 50+ and up to 5 cases of adults 15-49 (those best known to KI). Then ask about others the KI knows enough about to provide the basic information on this form.

Note: DK = do not know

PDA case number	1	2	3	4	5	6	7	8	9	10
Year of death (B.E.)										
Age										
Sex: 1=male; 2=female										
Marital status: 1=single; 2=married; 3=separated; 4=widow; 5=divorced; 6=remarried										
Did PDA have any dependent children (i.e. under 15)? 1=yes; 2=no										
Certainty level: 1=tested +; 2=sure but no test; 3=suspicious symptoms; 4=other										
Were the parents alive at time of illness? 1=father only; 2=mother only; 3=both alive; 4=both dead										
Did PDA live with a parent when ill? 1=yes; 2=no; 3=adjacent house; 8=dead before PDA										
If lived with parent, how long did PDA live with them during illness? 1=all the time; 2=much of the time; 3=a few months; 4=less than a month; 5=went back and forth; 8=DNA										
Did PDA live elsewhere before being ill? 1=yes and returned when ill; 2=did not live elsewhere or returned 2 or more years ago; 3=returned within 2 years but before being ill										
Who mainly took care of PDA? List up to two. **see supplementary codes.										
Did anyone else also help in a secondary role? List up to two. **see supplementary codes.										
How long before PDA died did they first become sick? Code in terms of months.										
Check if this is a KI-I case?										

Other comments (continue on reverse side if necessary)

Be sure to note which cases are related to each other (e.g. spouse, child).

Note: DK = do not know

PDA case number	11	12	13	14	15	16	17	18	19	20
Year of death (B.E.)										
Age										
Sex: 1=male; 2=female										
Marital status: 1=single; 2=married; 3=separated; 4=widow; 5=divorced; 6=remarried										
Did PDA have any dependent children (i.e. under 15)? 1=yes; 2=no										
Certainty level: 1=tested +; 2=sure but no test; 3=suspicious symptoms; 4=other										
Were the parents alive at time of illness? 1=father only; 2=mother only; 3=both alive; 4=both dead										
Did PDA live with a parent when ill? 1=yes; 2=no; 3=adjacent house; 8=dead before PDA										
If lived with parent, how long did PDA live with them during illness? 1=all the time; 2=much of the time; 3=a few months; 4=less than a month; 5=went back and forth; 8=DNA										
Did PDA live elsewhere before being ill? 1=yes and returned when ill; 2=did not live elsewhere or returned 2 or more years ago; 3=returned within 2 years but before being ill										
Who mainly took care of PDA? List up to two. **see supplementary codes.										
Did anyone else also help in a secondary role? List up to two. **see supplementary codes.										
How long before PDA died did they first become sick? Code in terms of months.										
Check if this is a KI-I case?										

Other comments (continue on reverse side if necessary)

Be sure to note which cases are related to each other (e.g. spouse, child).

Information about known or suspected current PWAs with symptoms

Instruction: Limit to a maximum of 5 persons who have experienced illness (do not ask about those who were never ill). Include all cases of PWA aged 50 and over.

Note: DK = do not know

PWA case number	21	22	23	24	25
Age					
Sex: 1=male; 2=female					
Marital status: 1=single; 2=married; 3=separated; 4=widow; 5=divorced; 6=remarried					
Did PWA have any dependent children (i.e. under 15)? 1=yes; 2=no					
How long has PWA been sick? Code number of months					
In what stage of AIDS is PWA? 1=full blown AIDS; 2=symptomatic HIV					
Certainty level: 1=tested +; 2=sure but no test; 3=suspicious symptoms; 4=other					
Are the parents alive? 1=father only; 2=mother only; 3=both alive; 4=both dead					
Does PWA live with parents? 1=yes; 2=no; 3=adjacent house; 8=parents dead					
If lives with parent, how long did PWA live with them during illness? 1=since before being ill; 2=much of the time; 3=a few months; 4=less than a month; 5=went back and forth; 8=DNA					
Did PWA live elsewhere before being ill? 1=yes and returned when ill; 2=did not live elsewhere or returned 2 or more years ago; 3=returned within 2 years but before being ill; 8=DNA					
Who mainly takes care of PWA? List up to two. **see supplementary codes.					
Did anyone else also help in a secondary role? List up to two. **see supplementary codes.					
Check if this is a KI-I case?					

Other comments (continue on reverse side if necessary)

Be sure to note which cases are related to each other (e.g. spouse, child).

Case # Comment:

Are you familiar with any parents in the area whose children left and died of AIDS elsewhere (i.e. did not return home when they were sick)?

___ No

___ Yes (number of cases _____)

Please provide the following information about these cases (up to 5)
(Be sure to limit to cases with a parent alive at time of illness)

Special PDA case number	26	27	28	29	30
Year of death (B.E.)					
Age					
Sex: 1=male; 2=female					
Marital status: 1=single; 2=married; 3=separated; 4=widow; 5=divorced; 6=remarried					
Which parent(s) were alive at time of illness? 1=father only; 2=mother only; 3=both alive					

Are you familiar with persons who became ill with AIDS in your area of responsibility but moved away before they died?

___ No

___ Yes (number of cases _____)

Please provide the following information about these cases (up to 5)

Special PWA case number	31	32	33	34	35
Age (when left)					
Sex: 1=male; 2=female					
Marital status (when left): 1=single; 2=married; 3=separated; 4=widow; 5=divorced; 6=remarried					
Did PWA have any dependent children (i.e. under 15)? 1=yes; 2=no					
In what stage of AIDS was PWA when left? 1=full blown AIDS; 2=symptomatic HIV					
Certainty level: 1=tested +; 2=sure but no test; 3=suspicious symptoms; 4=other					
Did he have a parent alive? 1=yes; 2=no; DK=do not know					
(if parent(s) alive, did the PWA go to live with parent(s)? 1=yes; 2=no; DK=do not know					

APPENDIX B
Information for persons who presented symptoms of AIDS in Bangkok
(KI-G/BKK, version 29 June 1999)

Date of interview: ____ Day ____ Month ____ Year
 Interviewer: ____ Chanpen ____ Wassana ____ Other (specify) ____
 Place: _____

Key informants:

	Name	Position	Duration in position
1.	_____	_____	_____
2.	_____	_____	_____
3.	_____	_____	_____

How many households in the community _____
 When was the first AIDS case in the community? _____

How would you describe the reaction of most people in the community to families that have some member get or die of AIDS? For example, are they indifferent, are they sympathetic, do they try to avoid them or what?

- ☐ most indifferent
☐ most avoid contact with family
☐ most criticize family
☐ most feel sympathy
☐ KI does not have opinion

Has the community reaction changed much since the first case of AIDS appeared?

- ☐ no
☐ yes, became more tolerant or accepting
☐ yes, became less tolerant or accepting
☐ other (specify) _____

Are there any organizations that help PWAs or their families who live in the area that your health center covers?

- ☐ No
☐ Yes (List them: _____)

Case Number	1	2	3	4	5
Q1 Still alive 1 yes 2 died (write year) 9 do not know	yr ____	yr ____	yr ____	yr ____	yr ____
Q2 Age (current or when died)					
Q3 Sex 1 male 2 female					
Q4 Marital Status 1 single 4 widow 2 married 5 divorced 3 separated 6 remarried 9 do not know					
Q5 Did PDA have any dependent children (i.e. under 15)? 1=yes; 2=no					

Case Number	1	2	3	4	5
Q6 Education 0 no schooling 1 primary or less 2 lower secondary 3 upper secondary/vocational 4 university 9 do not know					
Q7 Was PDA/PWA working when symptoms first appeared? 1 yes 2 no					
Q8 Indicate type of work or what PDA/PWA did (e.g. looking for work, student, housewife)					
Q9 Certainty status 1 tested positive 2 from symptoms only 3 from hearsay					
Q10 Place of origin 1 grew up in Bangkok 2 grew up elsewhere 9 do not know					
Q11 (If grew up elsewhere) How long was PDA/PWA in Bangkok before became symptomatic? 1 10+ years 2 2-9 years 3 1 but less than 2 years 4 less than a year 5 traveled back & forth 6 other (specify) 9 do not know					
Q12 How long was (has been) PDA/PWA symptomatic? (state in months)					
Q13 Were parents alive at start of illness? 1 father only 3 both 2 mother only 4 neither 9 do not know (skip to Q17)					
Q14 With whom did PDA/PWA live when symptoms first started? (indicate all that apply) 0 lived alone 1 with mother 2 with father 3 with spouse 4 with children 5 with relatives 6 with friends/non-relatives 7 with siblings 9 do not know					

Case Number	1	2	3	4	5
Q15 Did PDA/PWA move residence after becoming symptomatic? 1 no 2 yes, elsewhere in Bangkok, 3 went to home in province 4 went elsewhere but not to home in province 5 yes, but do not know where 6 yes, returned home to Bangkok 9 do not know					
If both parents dead (code 3 in Q13) skip to Q20 If lived with a parent (codes 1 and/or 2 in Q14), skip to Q19					
Q16 Where did the parents live when PDA/PWA became ill? 1 in Bangkok, another house 2 in the provinces 3 other (specify) 9 do not know					
Q17 Did PDA/PWA go live with parent after becoming ill? 1 yes 2 no 3 left parents when ill 4 other (specify) 9 do not know					
Q18 (If did not move) Did a parent come to live with the PWA in Bangkok? 1 yes 2 no 3 other (specify) 9 do not know					
Q19 If lived with parent when ill, how long did PDA/PWA live with them during illness? 1 all the time; 2 much of time; 3 few months; 4 less than mo.; 5 went back and forth; 8 DNA 9 do not know					
Q20 Who was main care giver (while in Bangkok)?					
Q21 Did anyone else help give care (while in Bangkok)?					
Q22 Is this cases a KI-I? 1 yes 2 no					

APPENDIX C

Form KI-I Detailed information for selected PDA/PWAs (15 April 1999-revised) (Administer after recording basic information for this case on KI-G form.)

Saw Aw ID: _____ Case ID _____ (This case is a _____ PDA _____ PWA)

Interviewer: _____ Chanpen _____ Wassana _____ Other (specify) _____

Date of interview: _____

Are informants the same as marked on the KI-G form?

____ Yes (Start questions)

____ No Informants 1) _____ Position _____
 2) _____ Position _____
 3) _____ Position _____

1. What was the economic status of the PDA/PWA before becoming ill?

- ____ very good
- ____ good
- ____ medium
- ____ poor
- ____ very poor
- ____ KI does not know

2. How open has the family been about the fact the person has AIDS?

- ____ Generally open to community
- ____ Open only to some (Check all that apply)
- ____ Open to close family
- ____ Open to health workers
- ____ Open to close friends
- ____ Did not admit to anyone having AIDS
- ____ Did not know or believe him/herself had AIDS
- ____ KI does not know

3. How did people in the community who knew PWA had AIDS react to the family during the time the PWA was ill?

- ____ people did not know, so no reaction (skip to 5)
- ____ not different than before/indifferent (skip to 5)
- ____ some reaction (Probe each of 1st five reactions and check all that apply)
- ____ some avoided contact with family
- ____ some were critical of PWA or family
- ____ some felt sympathy
- ____ some helped (specify how) _____
- ____ some visited PWA
- ____ other (specify) _____
- ____ KI does not know

4. (If both positive and negative reactions) Overall would you say the people in the community were sympathetic or negative in their reactions to the family during the time the PWA was ill?

☐ mainly indifferent
☐ sympathetic
☐ negative
☐ about equally sympathetic and negative
☐ other (specify) _____
☐ KI does not know

5. (If PDA) How did people in the community react to the family after the PWA died?

☐ people did not know so no reaction (skip to 7)
☐ not different than before/indifferent (skip to 7)
☐ some reaction (Probe each of 1st five reactions and check all that apply)
☐ some avoided contact with family
☐ some were critical of PWA or family
☐ some felt sympathy
☐ some helped (specify how) _____
☐ other (specify) _____
☐ KI does not know

6. (If both positive and negative reactions) Overall would you say the community reactions were sympathetic or negative in their to the family after the PWA died?

☐ mainly indifferent
☐ sympathetic
☐ negative
☐ about equally sympathetic and negative
☐ other (specify) _____
☐ KI does not know

- 6A. How did people in the community think of this person's character before he got AIDS?

☐ good person/well like person (khon dii)
☐ normal (pokati)
☐ frequent commercial sex patron (for man – 'tiew geng')
☐ promiscuous (for woman)
☐ bad person ('gaylay', 'puttigam mai dii')
☐ other (specify) _____

7. How did this PDA/PWA get AIDS:

☐ through commercial sex patronage
☐ through commercial sex work
☐ through spouse
☐ through non-commercial non-marital partner
 (specify type of relationship) _____
☐ through drug injection
☐ other (specify) _____
☐ KI does not know

8. How did PDA/PWA find out he/she get AIDS?
- ☐ went to get tested for HIV
 - ☐ went for pregnancy test
 - ☐ tested for other purpose (specify) _____
 - ☐ assumed from symptoms
 - ☐ never admitted having AIDS to self
 - ☐ other (specify) _____
 - ☐ KI does not know
9. You told me that _____ (from KI-G form) was/were the person(s) primarily taking care of the PDA/PWA. Was care-taking a serious burden for the care-taker(s)?
- ☐ not a serious burden
 - ☐ was a burden (probe each and check all that apply):
 - ☐ was a physical strain
 - ☐ was a emotional strain
 - ☐ was a financial strain
 - ☐ had to be with PWA all/most of time
 - ☐ other (specify) _____
 - ☐ KI does not know
10. How did this PDA/PWA make a living before becoming ill?
- ☐ did not work
 - ☐ (for PWA) still working (specify) _____
 - ☐ Worked (for PDA or PWA who stopped)(specify) _____
 - ☐ KI does not know
11. Was this PDA/PWA the main income earner in his/her family before becoming ill?
- ☐ Yes
 - ☐ No
 - ☐ other (specify) _____
 - ☐ KI does not know
12. If PDA/PWA was married, how did the illness affect the relationship with spouse?
- ☐ No change
 - ☐ spouse left because of AIDS
 - ☐ spouse left for other reason
 - ☐ spouse stayed under strain
 - ☐ other (specify) _____
 - ☐ KI does not know
13. With whom all does/did this person live (when ill with AIDS)? (Check all that apply)
- ☐ lived alone self
 - ☐ spouse
 - ☐ children (under age 16)
 - ☐ adult son (16+) ☐ adult daughter (16+)
 - ☐ father ☐ mother
 - ☐ father-in-law ☐ mother-in-law
 - ☐ brother ☐ sister
 - ☐ grand father ☐ grand mother
 - ☐ other (specify) _____
 - ☐ KI does not know

14. (If PDA/PWA changed residence after learning of infection or becoming ill as indicated in KI-G form) With whom all did PDA/PWA live before changing residence after learning of infection or becoming ill. (Check all that apply)
- ☐ lived alone self
☐ spouse
☐ children (under age 16)
☐ adult son (16+) ☐ adult daughter (16+)
☐ father ☐ mother
☐ father-in-law ☐ mother-in-law
☐ brother ☐ sister
☐ grand father ☐ grand mother
☐ other (specify) _____
☐ KI does not know
15. (If PDA/PWA changed residence after learning of infection or becoming ill as indicated in KI-G form) Why did the PDA/PWA change residence after learning of infection or becoming ill. (Check all that apply)
- ☐ Need someone to care for him/her
☐ Spouse died
☐ Spouse deserted
☐ Lost job or could not work any more
☐ Could not support self financially
☐ For psychological support (afraid or lonely)
☐ Came home to die
☐ other (specify) _____
☐ KI does not know
16. Were the expenses for the PDA/PWA's treatment or medicines substantial for the PDA/PWA or his/her family?
- ☐ yes
☐ no, did not get much treatment
☐ no, received treatment but covered by health card or other insurance
☐ other (specify) _____
☐ KI does not know
17. If there were expenses, who paid for these expenses? (Check all that apply)
- ☐ self
☐ spouse
☐ children
☐ parent(s)
☐ parent(s)-in-law
☐ sibling
☐ grandparent(s)
☐ other (specify) _____
☐ KI does not know

18. Were these expenses a burden for the family?
- ☐ yes, a serious burden
- ☐ yes, somewhat of a burden
- ☐ not much or none
- ☐ other (specify) _____
- ☐ KI does not know
19. Did the family have to sell land or possessions to pay for treatments?
- ☐ no
- ☐ sold or mortgaged land
- ☐ sold or pawned possessions
- ☐ sold both land and possessions (including mortgaged or pawned)
- ☐ borrowed money
- ☐ other (specify) _____
- ☐ KI does not know
20. Did any family member have to stop working to care for the PWA during time of illness?
- ☐ yes (specify who) _____
- ☐ no
- ☐ other (specify) _____
- ☐ KI does not know
21. Did any family member have to take on additional employment to help pay for expenses associated with illness and/or death of PWA?
- ☐ yes (specify who) _____
- ☐ no
- ☐ other (specify) _____
- ☐ KI does not know
22. Did PDA/PWA or their families receive welfare payments or help from any NGO when ill with AIDS?
- ☐ yes (specify) _____
- ☐ no
- ☐ other (specify) _____
- ☐ KI does not know
- [If PDA/PWA is an older person (50+), skip to last question.]
23. If not living with parents and one or both parents were alive, where did the parents live? (If parents are separated, answer re nearest parent; write place name and check appropriate category)
- Place _____
- ☐ in adjacent dwelling
- ☐ very nearby (within a five minute walk)
- ☐ in same community but not very nearby
- ☐ In same district, different community
- ☐ In same province, different district
- ☐ Different province
- ☐ KI does not know

24. If parent(s) are alive (or were alive when PDA was ill), how old are/were his parents?
 Father _____
 Mother _____
25. If parent(s) were alive, is/was the health of the parents at time of child's illness:

Father:	Mother:
___ good	___ good
___ minor problems	___ minor problems
___ poor	___ poor
___ very poor	___ very poor
___ KI does not know	___ KI does not know
26. If parents were/are alive, what was their economic situation before the PDA/PWA became ill?
 ___ very good
 ___ good
 ___ medium
 ___ poor
 ___ very poor
 ___ KI does not know
27. If parents were/are alive, do you think the parents' economic situation changed as a result of the PDA/PWA's illness?
 ___ did not change much
 ___ got noticeably worse (Check all reasons that apply)
 ___ from expenses associated with treatment
 ___ from expenses associated with funeral
 ___ from loss of income from the PDA/PWA;
 ___ from expenses for care of grand children
 ___ other (specify) _____
 ___ improved (specify reason) _____
 ___ other (specify) _____
 ___ KI does not know
28. If PDA/PWA has minor children, who cares for them since PDA/PWA is ill/dead? (check all that apply)
 ___ PWA alive and still cares for them
 ___ spouse of PDA/PWA
 ___ parent(s) of PDA/PWA
 ___ parents-in-law of PDA/PWA
 ___ other (specify) _____
 ___ KI does not know
29. If PDA/PWA has minor children, was their schooling affected by parents illness/death?
 ___ children already finished school by time of illness
 ___ no apparent effect
 ___ withdrew earlier than expected for financial reasons
 ___ performance suffered because of parent having AIDS
 ___ child is preschool age
 ___ other (specify) _____
 ___ KI does not know

30. How confident is/are the key informant(s) about knowing about the information asked about PDA/PWA?

_____ very confident

_____ reasonably confident

_____ does not know situation well

_____ other (specify) _____

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