

John Knodel and Chanpen Saengtienchai

**Older Aged Parents: The Final Safety Net for Adult Sons
and Daughters with AIDS in Thailand**

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Older Aged Parents:
The Final Safety Net for Adults Sons and Daughters with AIDS in Thailand

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John Knodel and Chanpen Saengtienchai

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Abstract

The AIDS epidemic in Thailand, as in other countries with significant numbers of persons with HIV/AIDS (PHAs), has created a major need for health care and material and emotional support for those infected and their families. The government and NGOs offer significant but limited health and welfare services to PHAs and their dependents. Compared to many of the poorest African countries where the AIDS epidemic is far worse, formal health and welfare assistance to PHAs and their families are probably far better in Thailand. Yet this formal safety net still leaves the bulk of care and support to be found outside such organized efforts. Under such circumstances, most needed assistance, both before and after death, is provided within the context of the family. Older age parents typically play a central role in caring for and supporting their adult sons and daughters when they become seriously ill with AIDS. In many cases other family members, especially non-infected adult siblings and spouses of the PHA also help. The fact that more than half of PHAs in Thailand eventually end up living with nearby parents at the final stage of their illness and that parents commonly provide care and support to their AIDS afflicted adult sons and daughters testifies to older age parents as the ultimate safety net in the context of the Thai AIDS epidemic.

AIDS remains a debilitating and fatal illness in Thailand as in most developing world settings. Although temporary periods of remission may occur following the onset of symptoms, eventual physical deterioration typically renders the infected person incapable of earning a living and at the terminal stage necessitates intensive caregiving. If the person with HIV/AIDS (PHA) has dependents, particularly young children, even after death there is a continued need for others to take responsibility for them. In Thailand, as in many countries where the AIDS epidemic is substantial, health and welfare services can offer only limited assistance to PHAs and their dependents. Under such circumstances, most needed assistance, both before and after death, is provided within the context of the family.

The present study focuses on the role of family members, especially of older aged parents, in the care and support of adults with AIDS and their dependents. Understanding the circumstances, nature, and extent of familial support and caregiving for AIDS afflicted persons and the role played by older aged parents and other members of the family network is crucial if the limited state and non-governmental resources designed to improve the quality of life of persons with AIDS and to ease the burden imposed by the epidemic on their families are to be appropriately targeted.

The Thai Setting

The AIDS epidemic

Thailand's AIDS epidemic began in the early 1980s and took off rapidly. By the early 1990s large numbers of persons were becoming ill and by the mid-1990s were dying of AIDS. Recent Thai government estimates indicate that at the start of 2000, almost 700,000 Thais were living with HIV/AIDS and that nearly 300,000 had died of the disease (Thai Working Group on HIV/AIDS Projection 2001). Although incidence has fallen in response to organized efforts to combat the epidemic, deaths are expected to hover around 50,000 a year for the next decade (Phoolcharoen et al. 1998); (UNAIDS 1998). While the adult prevalence level of 2 percent is modest compared to the worst hit African countries, it still places Thailand second only to Cambodia in Asia (UNAIDS 2000). Moreover, levels have been much higher in some areas of the country, especially in upper northern provinces where over 15 percent of military recruits tested seropositive in the early 1990s and tens of thousands of deaths attributable to AIDS caused the overall death rate to more than double between 1990 and 1996 (Im-em 1999; Nelson 1998; van Griensven, Surasiengsunk, and Panza A. 1998).

In common with most moderate and high prevalence countries, heterosexual intercourse has been the dominant route of HIV transmission in Thailand (UNAIDS and WHO 2000). Much of the epidemic has been driven by commercial sex patronage, a behavior that, at least until the AIDS epidemic became serious, had relatively little social stigma attached to it in Thailand (Knodel et al. 1996). More recently, infected men are increasingly spreading the virus to their wives and non-commercial partners (Chitwarakorn et al. 1998). Almost half of new infections are attributable to women infected by a husband or other partner (Thai Working Group on HIV/AIDS Projection 2001).

Socio-economic and demographic background

During much of the period associated with the AIDS epidemic, the country also experienced a continuation of the rapid economic growth that began several decades ago. However, Thailand was also at the forefront of the Asian economic crisis that came to a head in mid-1997 and spread rapidly to many other countries in the region (Gagnolati 2001; United Nations Development Programme (UNDP) 1999). Nevertheless considerable government effort was made, with assistance from international donor and development organizations, to mitigate the impact of the crisis on health and social welfare. Thus specific

efforts targeted the maintenance and even expansion of public low cost health insurance and social welfare programs.

Thailand is currently a low fertility country. The average number of live births a woman has, as indicated by the total fertility rate, has fallen from approximately 6 to 2 between the late 1960s and the early 1990s and has remained low ever since (2001). This has important bearing both for the number of adult children that an older age parent has and the number of orphans left behind by adult sons or daughters who die.

Exchanges of support and services between parents and adult children are pervasive in Thailand as in much of the developing world (Knodel et al. 2000; 1994). Widespread norms supporting filial obligations to parents underlie the existing system of intergenerational relations (Knodel, Saengtienchai, and Sittitrai 1995). At the same time, parents typically feel a continuing obligation to ensure their children's well-being. Living arrangements of older aged parents and adult children are closely linked to this system of support exchanges. One outcome is that approximately half of adult children with a living parent aged 50 and over live in the same local community as their parents and half of these coreside in the same household with parents. Moreover, the vast majority of adult children who live away from the parental community maintain contact. Almost 90 percent return to visit parents during a year and two-thirds of these visit at least several times.¹

Formal support for persons with AIDS and their families

Thailand also has a well developed public health system for a developing country. Local health stations and district hospitals are widely accessible. In recent years affordable health insurance is offered through several government programs. These include free medical care for persons age 60 and above, a voluntary low cost prepaid health card system that entitles up to five household members free access to government health services through a referral system, and a welfare program that covers medical costs for the indigent. In addition, employees of moderate and large enterprises have coverage through mandatory participation in the social security program instituted in 1994 and government employees have had their own health insurance scheme for many decades. Currently a program to provide universal inexpensive coverage is being implemented. Prior to late 2001, however, none of the various government health insurance schemes covered antiretroviral therapy (ART) for HIV although plans were being made to change this in the future.

As part of the Thai government's effort to deal with the AIDS epidemic, various welfare programs were established specifically targeted to persons with AIDS and their families under the jurisdiction of the Ministry of Labor and Social Welfare (see appendix for details). The most basic form of government welfare is a program that provides monthly allowances to the PHA that are terminated at the time of death. In recent years (1998 -2001), the amount allocated has remained more or less the same for these allowances and covers about 6000 person-years of assistance, the bulk of which went to a few provinces in the upper north². However, other programs of the Ministry address other situations. Taken together, the forms of assistance include both cash payments and assistance in kind. Assistance may be one time, several times, monthly until death, or even provide assistance to the dependents after the infected person dies. Targets for assistance of the various programs include infected persons generally, infected or affected women, infected heads of households, infected laborers, and children of infected persons. All

¹ The statistics cited are from original tabulations based on the Survey of Welfare of Elderly in Thailand (Chayovan and Knodel 1997).

² For example in 2001, about 60 percent of the total allocation went to just Chiang Mai and Chiang Rai provinces (out of 75 provinces nationally, excluding Bangkok which is excluded from coverage).

programs are intended for poor or indigent cases. In practice, these different programs are flexible in the manner in which they are applied. Older-aged parents of persons with HIV/AIDS however, are not targeted by any program.

A number of self-help groups have been established among people living with HIV/AIDS in Thailand that provide various types of support to members and their families. A survey of over 300 such groups, covering the large majority, was conducted from August 1999 to January 2000 by the AIDS Division of Ministry of Public Health and provides extensive information about the assistance they provide (Smitaketarin and Paowanaporn 2000).³ Almost all groups receive funding from the government, and particularly from the Ministry of Public Health. Many have been established by and/or are associated with government hospitals or health facilities although non-governmental organizations (NGOs) were involved in the establishment of a fourth. The large majority (85%) had been established during the prior 4 years. Although such groups exist in most provinces they are disproportionately concentrated in the upper north which accounts for close to half (46%). Activities of the groups are varied but most often include counseling (87%), caregiving assistance or advice (86%), and dealing with community relations (86%). About a fourth (26%) sponsor income generation activities. Only a small share provide financial assistance for treatment, care or funeral expenses (7%) and even fewer for expenses related to dependents (5%). All together the groups surveyed claimed a total membership approaching 19,000. Even allowing for the fact that a few such groups were missed by the survey, total membership would represent only a few percent of the estimated almost 700,000 infected persons at the start of 2000.⁴

There are numerous NGOs that have programs designed to assist persons with AIDS, although the actual numbers of cases reached by these programs are far less widespread than those of the government (Im-em and Suwannarat 2002). One organization, HelpAge International, does sponsor programs in Thailand (and elsewhere) explicitly directed towards parents but the actual number of persons involved so is very modest {HelpAge International Asia Regional Office undated #6400}.

Data Sources

In this paper we draw primarily on three components of a comprehensive research project designed to study the impact of the AIDS epidemic on older persons in Thailand: interviews with key informants about individual AIDS cases and their families; direct survey interviews with parents who lost an adult child to AIDS (whom we refer to as AIDS parents); and open-ended interviews with AIDS parents.⁵ The first two permit quantitative analysis while the third is suited for qualitative analysis. Table 1 indicates the provinces represented and their HIV prevalence as reflected in military recruits, and the number of cases by each data source. A brief description of each source follows. Detailed accounts of the methodology involved in each component are available elsewhere (Knodel et al. 2000; Saengtienchai and Knodel 2001; Knodel et al. Forthcoming).

³ Some of the statistics cited in this paragraph were calculated by us based on raw numbers in the report rather than direct citations of published results.

⁴ The coverage of the estimated 68,000 persons who already developed AIDS might be greater if there share of membership compared to others who are HIV positive but have not developed AIDS is disproportionately large as might well be the case (Thai Working Group on HIV/AIDS Projection 2001). However, clearly not all members have progressed to AIDS and thus the large majority of AIDS cases are not members.

⁵ For details of the methodology these sources see of (Knodel et al. 2000; Knodel et al. Forthcoming; Saengtienchai and Knodel 2001).

[Table 1 about here]

Specific sources

Key informant study. The key informant study involved interviews with persons knowledgeable about individuals who were living with or who died of AIDS in the community. Most informants were paid staff or volunteers associated with local health centers. Interviews took place during 1999 in 85 sites in rural and urban communities in 8 provinces around the country and in Bangkok. The provinces represent a fairly wide range of HIV prevalence levels. The study yields basic information on living arrangements and caregiving for over 1000 individuals. In addition, for almost 300 cases whom the informants knew best, we asked for supplemental details about the living and caregiving arrangements as well as sources of support.⁶

Direct interview survey. The direct interview survey involved a detailed structured questionnaire administered directly to parents who lost at least one adult child to AIDS, usually within the prior three years.⁷ The survey took place during 2000 in three provinces that were included in the key informant study. In two (Chiang Rai and Rayong) HIV prevalence is relatively high (for Thailand) and in the third (Phichit) prevalence is much more moderate. In total, we conducted 394 interviews with AIDS parents. However, in cases where both parents were alive and living together, certain items in the questionnaire were asked separately for each parent. Thus the interviews generated information for 649 individual AIDS parents (363 mothers and 286 fathers).

Local health personnel served as intermediaries in identifying cases of AIDS parents to interview. We eliminated a small number of cases from consideration whom the intermediary believed would be unwilling to be interviewed. In most sites, the large majority of the remainder who were initially identified agreed to be interviewed. In order to make the actual interviews with AIDS parents less sensitive, we did not refer to AIDS as the cause of their child's death during the interview although most admitted that their deceased son or daughter had died AIDS when asked about the cause of death.

Open-ended interviews. We also conducted 19 open-ended interviews during 1999 with AIDS parents. The cases were drawn from Bangkok and three provincial settings. The interviews cover many of the same issues as the direct interview survey but their open-ended nature encouraged interviewees to elaborate on these issues and the circumstances affecting them. The interviews were recorded and fully transcribed.

Comparison of sources

There are serious methodological challenges to obtaining accurate and representative information about parents of persons with AIDS and any practical approach is likely to be prone to some type of bias. The three data sources described above are no exception. The open-ended interviews are based on a small number of cases and thus are only illustrative. Moreover, while both the key informant study and the direct interview survey provide sufficient cases for quantitative analysis, neither is based on a probability

⁶ For most purposes, our analysis is limited to 768 cases of adults who died locally, among whom supplemental information was collected for 258.

⁷ We also interviewed a comparison group of parents of similar ages and backgrounds from the same survey sites who did not experience the loss of an adult child. We do not draw on these interviews, however, in the present analysis.

sample and can not be generalized in any rigorous fashion. Nevertheless, we believe that, taken together, our multi-method approach provides considerable insight into the situation.

The key informant study and the direct interview survey have complimentary strengths and weaknesses. All information from the key informant study about the PHA and their parents were provided by a proxy. In the direct interview survey, AIDS parents provided information about themselves and about their own deceased son or daughter. Thus the direct interview survey provides more detailed and almost certainly more accurate information for any particular individual case. The key informant study, however, is likely to be more broadly representative of AIDS parents in general.

In the key informant study, informants were asked to identify adults in the local community who were currently symptomatic or who had died of AIDS. All cases were included regardless of whether the parents were alive or dead or where they lived. In the direct interview survey, we asked the intermediaries to identify parents who lived in the local area and who had lost an adult child to AIDS either locally or elsewhere. The intermediaries were generally able to identify parents whose child died locally since local AIDS deaths are typically known, especially to health personnel. However, they found it difficult to identify those parents whose child died elsewhere since the child's death would not necessarily be known to them. Hence the direct interview survey is skewed towards cases in which the parents and the deceased son or daughter were living in the same community, at least at the terminal stage of illness (including cases in which the deceased adult child returned to the parental community after becoming symptomatic).

The under-representation of parents whose child died away from their locality in the direct interview survey is important because such parents are less likely to be involved with caregiving and support of their child during the period of illness. This bias is evident from the higher percentages of cases (71 versus 59 percent) for which a parent was a main caregiver as indicated by the direct interview survey compared to our estimate from the key informant study (based on cases with a living parent). However, there is less reason to expect that the direct interview survey provides biased information about caregiving and support among the large group of parents who were involved in providing care. Also unlike the direct interview survey, information from the key informant study is not limited to parents who were willing to be interviewed, another feature that makes the latter data more broadly based.

Previous analysis indicates that the age distribution of AIDS parents as reported both in the key informant study and the direct interview survey closely resemble the expected distribution based on a nationally representative general household survey (Knodel 2001). All three distributions indicate that the vast majority of AIDS parents are at least age 50 and approximately half are 60 or older. The AIDS cases reported by the key informants and the direct interview survey in the direct interview survey also fairly closely resemble the national caseload of adult cases as represented by the national AIDS registry with respect to age, sex and marital status distributions (Knodel and VanLandingham 2001; Knodel et al. 2000).

Some clarifications

Living and caregiving arrangements often change for persons with AIDS during the course of the illness. Many initially care for themselves but at later stages require assistance. However substantial return migration occurs at advanced stages of the illness among those living away from their parental home (as shown below). Thus the extent of parental involvement in caregiving and other forms of support during illness is fully evident only for cases who have already died of AIDS. For this reason, we limited our samples of AIDS parents in the direct interview survey and in the open-ended interviews to cases in which the adult child had died. In addition, although the key informant study included cases of persons who were currently symptomatic, we restrict our analysis to those cases in which the adult with AIDS had already died.

In both the key informant study and the direct interview survey, more than one person was allowed to be designated as a main caregiver. In most cases only one person was so designated. Nevertheless in some cases where a parent is designated as a main caregiver another person (including the other parent) could also share this designation. In direct interview survey respondents could also state up to two persons as the main contributors to care and treatment expenses. In most cases, however, only one person was so designated as the main care giver or the main contributor.⁸

In interpreting the quantitative results presented below, it is useful to recognize that the unit of analysis varies with the particular issue being addressed. Some analyses refer to the person who died of AIDS while others refer to their parents, family, or orphaned children. For convenience, we use the term ‘case’ to refer to whatever the particular unit of analysis is that for the tabulation being described. Since many questions about parents in our study refer collectively to the mother and father together if both were alive and since we only focus on one deceased adult child of the parents per interview (even if more than one child died of AIDS), there is a direct correspondence between AIDS parents and adult children as units of analysis. In this sense the two are interchangeable as ‘cases’.⁹ More generally, results in the tables are sometimes conditioned on subsets of cases and thus are based on varied numbers of cases.¹⁰

Results

We start our presentation of results by examining the extent to which the actual receipt of formal assistance is reported and how much this helped meet the expenses associated with care, treatment and support. Next we discuss the prevalence of and pathways to parental caregiving of adult children with AIDS. This is followed by a more specific examination of the duration, the tasks involved and the assistance parents received from others. We then examine the role of parents and other family members in economic support of adult children with AIDS. Finally we discuss the role of AIDS parents in economic support and care of AIDS orphans.

Extent of formal assistance

As noted above, several important formal channels of assistance are available in Thailand that help cover expenses associated with the treatment, care and support of persons with AIDS. These primarily include inexpensive or free government health insurance and welfare programs targeted particularly to persons with AIDS and their families.

⁸ For example, in the direct interview survey, which allowed up to two persons to be so designated, 12 percent of the cases where at least one parent was considered a main caregiver, the other parent was also designated as such; in 16 percent a parent shared the role with someone other than his or her spouse; and in the remaining 72 percent, a parent was the sole main caregiver. In 9 percent of the cases in which a parent was a main contributor to expenses, this role was shared with someone else.

⁹ As noted, some questions asked for information separately about each parent alive during the child’s illness. In analyzing information from such questions, the number of parents would be greater than the number of deceased adult children for whom we have data. However, the present analysis does not involve tabulations based on individual parents.

¹⁰ In addition to this reason, the number of cases may vary slightly from table to table because of differences in missing data for questions when the informant could not provide an answer or because a few questions in the key informant study were added shortly after fieldwork started and thus not asked at the first few sites.

The key informant study did not ask directly if the person who died of AIDS had health insurance. However, for the subset of cases for which supplemental information was collected, key informants were asked if the person who died of AIDS or his or her family had substantial medical expenses. If the informant mentioned in response to this question that insurance helped pay for treatment and medicines this was noted. Responses to this question thus provide a minimum estimate of the extent of health insurance coverage in cases of AIDS. Table 2 shows the results in relation to the economic status before the illness of the person who died of AIDS and his or her parents if they were known to be still living.¹¹ Despite the fact the question did not directly ask about it, health insurance was mentioned as helping with medical expenses in over half of cases. Moreover, the percent noted as having such insurance is inversely related to the economic status of both the PHA and his or her parents. This inverse association, at least in part, likely reflects the deliberate practice of providing health expense assistance in cases of with AIDS who could not afford it.

[Table 2 about here]

The key informant study did include a direct question for the subset of cases for which supplemental information was collected about receipt of welfare. In just over a fifth (21%) of the cases, the persons who died of AIDS or his or her family received some sort of welfare assistance. Moreover, those of poor economic status as well as those whose parents were poor were substantially more likely to receive welfare than those who were average or better off.

Table 3 provides results based on the direct interview survey regarding the extent to which health insurance and welfare assistance was received by adult children with AIDS or their families. AIDS parents were asked directly if health insurance helped pay for any of the medical costs during the time of their child's illness. Results are shown in relation to economic status of the parents.¹² In approximately three-fifths of all cases covered by our survey, some form of health insurance helped pay for the medical costs of the adult child who died of AIDS. Health insurance was somewhat more likely to cover at least some medical costs when the parents were of average or poor economic status than if they were better off. The overall prevalence of health insurance indicated in the direct interview survey is somewhat higher than in the key informant study, probably reflecting the fact the key informant results are not based on a direct question. Both sets of results are consistent in the sense of pointing to widespread use of health insurance to defray medical expenses among persons with AIDS.

[Table 3 about here]

The vast majority of cases in which insurance helped pay medical expenses involved some government program. Very few cases had private health insurance. By far the most common insurance was the

¹¹ Socio-economic status of the parents in the key informant study is based on the judgement of the key informant.

¹² The measure of household economic status for the direct interview survey is based on two items: self assessed economic status of the respondent relative to others in the community and the interviewer's judgement of the respondent's status based on the appearance of their dwelling. Each question allowed 5 different rankings from very well off to very poor. We assigned a score of 1 for very poor to 5 for very well off and summed the answers to the two items resulting in 9 possible scores ranging from 2 to 10. These scores were then grouped to form three broader categories. To determine the break points between categories we examined cross tabulations of the of summed scores and the percent of households possessing selected appliances (e.g. color television, refrigerator) and motor vehicles. We chose break points that corresponded well with differences in terms of these percents.

voluntary government health card scheme in which membership can be purchased for a modest amount by families not covered by other programs. In addition, a substantial share were covered through welfare. Civil service benefits and the social security system also accounted for a minority of the medical payments. The percentage of cases in which medical expenses were paid at least in part through welfare is inversely related to the economic status of the parents while the reverse is true for the percentage receiving coverage through civil service or social security.

Responses to a question about the extent to which the health insurance helped with expenses, indicate clearly that these schemes were of considerable assistance. Only 10 percent of the cases for which health insurance was used indicated it was of little help. More than half (56%) of those who received coverage indicated that it helped a great deal and over an additional third said it helped at least some. The percent who indicated that insurance helped a great deal is inversely related to the economic status of the parents. Even for better off parents, however, the insurance appears to have been of substantial help in almost half of the cases.

The direct interview survey also asked about welfare assistance in connection with AIDS to the deceased child or his or her family. Overall almost a fifth reported receiving some sort of welfare, a result consistent with the findings reported above from the key informant study. These payments typically were made to the person who was ill with AIDS and not directly to the parents. Nevertheless, parents as a common contributor to expenses presumably benefited in many such cases. Receipt of welfare assistance was substantially higher among cases in which the parents were poor than among other cases.

In general the period during which welfare was provided was often short. In over two-fifths of the cases who received welfare, payments were made for only a month or less (some being one time assistance). About the same proportion of cases, however, either reported receiving welfare for six months or longer or reported that the family was still receiving some welfare payments. Cases in which parents were poor seem to receive welfare somewhat longer than others.

The amount received as welfare payments are relatively modest compared to typical total expenses involved in care, treatment and funerals. The mean amount received of just over 10,000 Baht compares to a mean of almost 34,000 Baht that parents paid for care and treatment and over 18,000 Baht paid for the funeral (Knodel et al. Forthcoming). Even though the combined costs of care and funerals were considerably less than average for those who received welfare (as judged by the means), the amount received by welfare averaged only about a third of the costs reported (results not shown in table). This may explain why the most common response concerning the extent welfare helped with expenses was that it did not help much. Only about a fifth (19%) of those who received welfare said that the payments helped very much. This percentage, however, was higher for those in which a parent was a main contributor to expenses (not shown) and is inversely related to the economic status of the parents.

The open-ended interviews confirm the importance of government health insurance in meeting the medical and other health related expenses. Quite a few of those we interviewed mentioned that all or most of these cost were covered by the prepaid health card system or that they were issued a health card free. Still for those who were poor, the expenses that were not covered, such as transportation to health care sites and the costs of some medicines, even if they were subsidized, could be difficult to meet.

Interviewer: Did you pay a lot of money for medical treatments?

Mother: Later I didn't have to pay because I had a health card. If I had to pay them myself, it would be more than 100,000 Baht.

[51 year old mother, middle income, Rayong]

Interviewer: Did you pay a lot of money for his treatment and other things while he was sick?

Father: I had to pay at the hospital. He also asked for a support as a destitute person... so we paid only half.

[65 year old father, poor, Bangkok]

His brother who was working at a hospital told me that he couldn't live for more than 3 months.

After that, he went to see the doctor all the time. He lived for more than a year and didn't have to pay for medical expenses because he had a health card.

[67 year old mother, poor, Chiang Mai]

The various health insurance and welfare schemes did not always help. In one case, the ill son who was entitled to reimbursement for medical service fees by virtue of being a military officer, refused to ask for it because he wished to keep his condition confidential. In another case, bureaucratic complications prevented a poor family from getting a low income card that would have entitled the PHA to mostly free health. As a result the health care costs they did have, although modest in an absolute sense, created a considerable financial strain for them. Bureaucratic delays could also contribute to why so few who did receive welfare assistance believe it helped very much, as the following case illustrates.

We took him to ask for money (at the welfare office). When we went to apply, he was still able to walk. I didn't expect him to die. Up until he became very ill, we still didn't received the money. We thought we would never get it... Then, they sent us a letter that we could go and get the money. I got the money and gave it all to monks to make merit for him because he was already dead.

[61 year old mother, poor, Phetchaburi]

In sum, between the two main types of formal assistance with the expenses associated with AIDS in Thailand health insurance not only is considerably more widespread but is more likely to be reported as having helped significantly among those who used it than welfare assistance (including help from NGOs). A considerably smaller share of cases benefited from the latter and only in a modest minority of these cases was the welfare assistance reported to have helped very much. Two caveats, however, should be mentioned. First, some of the health insurance was provided as a form of welfare even though counted as the former in our analysis. Second, at the time of our research, health insurance did not pay for anti-retroviral therapy and indeed most persons with AIDS and their families were probably unaware of its existence. Had they known more, the demand for this expensive form of treatment would almost certainly have been greater and perceptions of the extent to which health insurance helped might have been very different. The situation is changing rapidly in Thailand in terms of awareness, availability, price and insurance coverage related to these formerly very expensive drugs and thus our results may not reflect what will be the situation in the not too distant future.

Parental caregiving: prevalence and pathways

Older Thais are intensively and extensively involved with their infected adult children though both living and caregiving arrangements. As discussed above, the key informant study provides us with the most representative findings regarding the prevalence of these situations (see figure 1). According to those data, two-thirds of adults who died of AIDS either lived with or next to a parent at the terminal stage of illness. Parental caregiving is also extensive. Almost two-thirds of adults who died of AIDS received at least some personal care from a parent and for half, a parent was a main caregiver. The percentages are even higher if we consider only those deceased adults who had living parents at the time of death.¹³ For

¹³ In order to derive estimates of living and caregiving arrangements conditioned on having at least one parent alive, the results were adjusted for the 8 percent of cases for which the key informant did not know if the parents were alive. For details see (Knodel et al. 2001)

example, in such cases coresidence at the terminal stage reaches 70 percent and for almost 60 percent, a parent was a main caregiver.

[Figure 1 about here]

The direct interview survey also provides information on who contributed to personal care giving during the terminal stage and whether or not the person was a main caregiver. Closely associated with personal care giving, is assistance outside the household (e.g. helping with transportation, shopping, or arranging for welfare benefits). We also asked specifically who provided such instrumental help in the direct interview survey (but not in the key informant study). As noted above, for a modest number of cases, more than one person played a major role in the caregiving and thus occasionally the mother and father of the same adult child are both considered as main caregivers. When interpreting comparisons between the roles of mothers and fathers in personal caregiving and instrumental help, it is useful to take into account whether both or only one parent is alive.¹⁴ Data from the direct interview survey allow us directly to condition examination of the role of each parent on situations where both parents are alive.¹⁵

There is a clear gender dimension to parental personal caregiving as table 4 shows. Mothers are more likely than fathers to provide personal care and are particularly more likely to be a main caregiver. The gender differential reflects in part the greater likelihood that an adult PHA has a surviving mother than a surviving father as revealed by comparing results from the direct interview survey based on all cases and those conditioned on having both parents alive. Nevertheless, even for cases in which both parents were alive, the mother was 2.8 times more likely than the father to be a main care giver. Instrumental help shows far less pronounced gender differentials. When both parents are alive, fathers and mothers are about equally likely to provide some instrumental help and mothers are only 20 percent more likely than fathers to be the main provider of instrumental help.

[Table 4 about here]

In understanding the high prevalence of parental caregiving to adults with AIDS in Thailand, it is useful to recognize that there are three basic routes that lead the adult children to be with or near parents at the terminal stage of illness. In many cases the son or daughter is already living with or in the vicinity of the parents at the time symptoms first appear. In many others, the adult child lives elsewhere and returns to the parental community only after becoming ill. A third route involves the parent going to the where the ill adult child lives to provide care and support.

As noted in the discussion of the Thai setting, about half of adult children of older-age parents live with or nearby them even under normal circumstances. Such residential proximity obviously promotes parental involvement during times when a son or daughter falls ill. At the same time, substantial return migration of ill adult children, especially in cases of a fatal and incurable disease such as AIDS, is frequent.

¹⁴ Based on the age distribution of persons who died of AIDS as stated in the latest Thai national projections and information of the survival status and age of mothers and fathers of adults of different ages in the general population from a 1994 national household survey, we estimate that during the period 1996 - 2000 there is about a 25 percent greater likelihood that the mother than the father of an adult AIDS case to be still living.

¹⁵ Such direct conditioning can not be done with the key informant study data because allowance needs to be made for cases in which the living status of the parents is unknown.

Many young adults in Thailand migrate from their parental home in order to find work. This is particularly evident in rural areas where young adults often go to urban centers, especially Bangkok (1995; Fuller, Lightfoot, and Kamnuansilpa 1990). Marriage also leads some children to move away to their spouse's community. Thai hospitals shy away from long term care of AIDS cases and hospices for persons with AIDS have very limited capacities. Unless adult children who leave their home communities are married and their spouse remains with them to provide care and financial support, they often have little choice but to return to their parents. Even for married children living away, the need for assistance in caregiving or material support may prompt the couple to move to live with parents. Moreover, persons with AIDS may have strong personal emotional reasons for wanting to be at home to die.

Both the key informant study and the direct interview survey suggest substantial return migration. According to the former, 40 percent of adult children who were cared for by parents at the terminal stage had returned home from elsewhere. The percentage indicated by the direct interview survey (32%) is somewhat lower but still considerable. For both sources the percent of return migrants is higher among daughters than sons who received care. This may reflect a lesser tendency for husbands than wives to give care when a spouse falls ill as well as a tendency for husbands to predecease wives in couples in which both are infected.¹⁶ To make a more definitive interpretation of these gender differences, however, we would need to relate the number of return migrants to the 'population at risk' of return, i.e. all adult children with parents in the locality who became ill when living away, regardless of whether or not they returned. Unfortunately, we lack sufficient information on the numbers who do not return. Thus the higher proportion of return migrants among daughters compared to sons could simply reflect that a higher proportion of daughters than sons are living away from their parental home at the times they become symptomatic. We have no way of knowing if this is the case from our data.¹⁷

In many cases, adult children with AIDS who return to their parents do so at an advanced stage of the illness. The direct interview survey indicates that almost one fifth (19%) of those who returned after the onset of symptoms died within less than a month and almost half (46%) died within three months. The key informant study agrees well with this indicating that 47 percent of adult children returned from elsewhere and both lived with and were cared for by their parents died within 'a few' months.

Because we lack adequate information about cases in which the adult child died of AIDS but was not living with or near a parent during the time of illness, it is difficult to assess the extent to which parents go to their child (rather than the child returning) to provide care and support. The little information we do have from the direct interview survey suggests this may also be common. In just over three-fourths of the small number (25) of cases in which the deceased child remained outside the parental locality until death, parents reported that they spent time with the child during illness. Among those who did spend time with

¹⁶ Both the key informant study and the AIDS parents study indicate a clear gender differential in caregiving among husbands and wives. For example, the key informant study indicates that among married persons who died of AIDS, wives provided personal care for 77 percent of husbands with AIDS but husbands provided personal care in only 47 percent of wives with AIDS. Equivalent results from the direct interview survey are very similar (78 percent versus 48 percent). Both sources also show that husbands are much more likely to predecease wives than the reverse. Among ever-married adult children who died of AIDS, the key informant study indicates 31 percent of daughters compared to only 7 percent of sons were widows or widowers. Equivalent results from the AIDS parents are very similar (35 percent versus 10 percent).

¹⁷ For a fuller discussion of return AIDS migration and the methodological problems associated with estimating rates of return see (Knodel and VanLandingham 2001).

the child, almost all said they provided at least some personal care and about two-thirds reported they were a main caregiver. These results are likely biased upwards, however, since the intermediaries who identified these cases are likely to be more aware of those in which parents were active than cases in which the parents did not visit their ailing adult child.

The open-ended interviews reveal that underlying the basic routes to parental caregiving and support, much variation exists. Cases in which an adult child coresided with parents or lived very nearby before any symptoms presented themselves included some in which prior coresidence with parents has existed since childhood. In others, however, the adult child had more of a come-and-go arrangement, periodically spending time away from home, often in connection with work (e.g. as a fisherman or as a member of a traveling troupe of entertainers). Coresidence or living nearby sometimes included a spouse who might also play a major role in caregiving. Cases in which the deceased adult child was living and working elsewhere when symptoms first emerged included some in which the return was straightforward but others in which a complicated series of moves were made before the child finally died including cases in which the child was initially coresident and left for elsewhere only to return later. In some cases, a spouse accompanied the ill child and joined the parents in caregiving but did not necessarily remain until the end.

These varying degrees of complexity in the routes to parental caregiving and support arise from a host of sources. Living arrangements are fluid and can be influenced by the progression of illness associated with AIDS, the search for treatments, work requirements, and social dynamics among family members, including the breakup of an infected child's marriage. Stays many cases of initially non-coresident children, not infrequently it is the parents who urge the adult child to come back home, although sometimes the child may be reluctant to do so.

Caregiving specifics.

Caregiving duration. Regardless of the route through which parental caregiving arises, its duration usually is a matter of months. Table 5 shows parental caregiving duration both for those adult children who were living in the parental locality before the onset of symptoms as well as those who returned after becoming ill. On average the duration of caregiving is modestly shorter for those who returned from elsewhere. For approximately a third of both groups, however, caregiving lasted less than a month and even for those who were in same community from the start, less than a fifth were given care for 6 months or more. The moderate duration of parental caregiving probably reflects a combination of short survival times after the onset of AIDS in Thailand and attempts on the part of many adult children to take care of themselves as long as they are able. Although the duration of parental caregiving may be modest, it occurs during the most disabling stage of the illness and is thus likely to be intensive as well as particularly emotionally and physically draining for both parent and child.

[Table 5 about here]

Caregiving tasks. Caregiving to an adult child with AIDS can involve a wide variety of tasks ranging from those that likely would be done even for a healthy coresident child to others that are associated with the extreme debilitation that often accompanies the last stages of AIDS related illnesses. Variation in disease progression and the particular opportunistic infections that the child develops contribute to diverse experiences among caregiving parents.

In the direct interview survey, if either parent gave any personal care or instrumental help to their deceased child, respondents were asked what specifically they had done. If a specific task was not mentioned spontaneously, the respondent was probed by the interviewer about it. When both parents were involved, the question referred to their combined efforts and did not distinguish between tasks done by each. Thus it is not possible to examine gender differences in specific tasks directly. However it is

possible to distinguish among cases in which only a mother, only a father or both parents assisted. The results are shown in Table 6 in the order of the frequency with which they were mentioned. In a majority of cases in which only the mother or only the father provided assistance, the other parent was deceased (63 and 58 percent respectively - results not shown).

[Table 6 about here]

For the full set of parental caregivers, the most common task was watching over the ill adult child followed by food preparation. In a majority of cases, a parent had to help with very basic needs such as feeding, using the toilet, bathing and dressing. Several tasks involving instrumental help were also quite common, especially shopping for food and providing transportation for the ill son or daughter. Other instrumental help such as applying for welfare and managing financial affairs were relatively uncommon. The results show that parents are often involved in the interactions between the ill adult child and the health system, including transporting the son or daughter to health facilities, helping administer medicines, and consulting with health care personnel.

Clear differences are apparent in the frequency with which most tasks were mentioned according to which parent provided assistance. For almost all tasks, the percentage doing the task is higher when both parents jointly assisted the ill child than when only one parent was involved. However, the percentage mentioning specific tasks typically was only modestly lower when just the mother was involved rather than both parents. In contrast, when only the father provided assistance, many tasks were substantially less likely to be done. Some caution is called for in interpreting the differences between cases in which only the mother and only the father provided assistance given the small number of cases of the latter.

Results from the open-ended interviews are quite congruent with the survey data and shed additional light on the nature of caregiving. The most frequently reported tasks involved those directed towards meeting the ill child's needs of daily living: preparing food, doing laundry, and assisting in eating, dressing, bathing, and using the toilet. In cases where the adult child was already coresident, some of these tasks represented a continuation of the situation prior to the onset of illness. Where the PHA moved in from elsewhere, however, it meant that additional food needed to be procured and prepared. More significantly, most parents modified their normal food preparation in one or both of two ways. Some tried to structure the child's diet to consist of foods they believed were particularly healthy and to avoid foods considered as potentially harmful to the child's condition in hopes of restoring the child's health or at least slowing further deterioration. Others tried to please the child by preparing favorite dishes, providing anything the child wished, or serving dishes that were seen as especially delicious but that normally would be reserved for special occasions because of their cost. This latter approach was motivated both out of sympathy for the child and as a way to keep up the child's strength. Not infrequently, parents combined the two strategies.

I was careful (about what he ate). I wouldn't let him eat cold food because he was hot inside. It's like he had a fever all the time. I also didn't let him eat seafood.

[61 year old mother, poor, Phetchaburi]

I bought him bird's nest soup when I still had money... At that time, I bought him good food because I knew that he would not live for long. I just bought him any food he craved.

[59 year old mother, poor, Rayong]

I saw his body getting thinner each day. So, I never told him not to eat. I let him eat whatever he liked.

[65 year old mother, poor, Rayong]

Several parents mentioned that eventually their children became too weak to eat on their own and had to be spoon-fed. Many were concerned that their child was not eating enough, could not keep food down, had frequent diarrhea and/or was losing weight. Thus they encouraged the child to eat even if at the same time they avoided giving food that they saw as risky for the child's condition.

Doing laundry for the sick child was also mentioned in a number of open-ended interviews. As with food preparation, this did not always represent a new chore. However, at the more advanced stages of illness it could involve sheets and clothing that were soiled by urine or excrement adding a new, unpleasant dimension to washing them and one that sometimes caused the parent concern about the possible risk of contagion. Problems associated with incontinence or in helping the ill child access the toilet were particularly salient. Especially towards the later stages of illness, many of the persons with AIDS were unable to walk on their own and needed help to get to the bathroom to bathe or relieve themselves. In rural settings, the toilet and bathing facilities are usually outside the house, making access all the more difficult. Providing assistance to the toilet in the middle of the night was particularly inconvenient. Also, in some cases, the available caregivers lacked the physical strength to carry or hold up the PHA. Nevertheless, as unpleasant and burdensome as these aspects of caregiving could be, most parents accepted it in a matter of fact manner.

At first he still could go to the bathroom but later he couldn't. He would call me when he peed on himself. I understood that he couldn't control that. Later, I had to buy diapers for him. Then I had to clean his butt.

[51 year old mother, middle income, Bangkok]

I had to clean up after he defecated. If he could use a bed pan, he would use it. At his later stage, he couldn't go to the bathroom anymore. He would defecate in bed.

[61 year old mother, poor, Phetchaburi]

Mother: At first he could go to the toilet himself but when he got really sick, he had to use a bed pan.

Father: Both of us had to help. We had to drag him... We had to dig a hole near the place where he slept. When he needed to defecate, we dragged him to the hole.

[70 year old mother and 80 year old Father, middle income, Rayong]

The open-ended interviews also confirmed that visits to and stays in health care facilities typically involved the presence of family caregivers. Visits to such facilities were not infrequently made at the parent's urging and often a parent accompanied the patient. Others besides the main caregiver, typically fathers and brothers of the ill persons, assisted in providing transport to health facilities and, when necessary, helped in lifting or propping up the PHA when walking. In Thailand it is not unusual during hospital stays for a relative to remain with the patient even staying overnight. In some circumstances it was virtually a necessity as the in-patient care provided by the hospital staff was seriously deficient, at least in the eyes of the parents. In other cases the motivation seems largely to provide moral support.

We went to the (provincial) hospital quite often. It's crowded. Sometimes, there's no bed available... Any available space like near the stairs. He slept there. The hospital allowed one person to closely watch him. When he got a fever, I wiped his body. If he wanted to pee, I had to help him because sometimes he couldn't go to the toilet by himself. (Nurses) came only at the time to give medications... When I went to sleep, I leaned over the bedside.

[51 year old mother, middle income, Rayong]

I stayed at the hospital. I didn't come home at all. My daughter was scared. When I was about to leave, she would ask me not to go. She would hold my hands. She didn't want me to be out of her sight.

[57 year old mother, middle income, Rayong]

Assistance to parental caregiving. Although parents frequently were involved in care giving, they were not necessarily alone in taking this responsibility. Table 7 indicates who else helped when parents were involved in personal care giving and instrumental help activities based on the direct interview survey. The table is limited to cases in which at least one parent assisted the adult child who died in the particular type of assistance specified. Parents who provided personal care were assisted by others in just over two thirds of the cases and in just over half of the cases when they provided instrumental help. Assistance from others was somewhat less common when a parent was a main personal caregiver as well as when a parent was a main provider of instrumental help. This might reflect a selection process through which parents are more likely to become the main personal caregiver or provider of instrumental care if no one else was available.

[Table 7 about here]

The most common persons to help AIDS parents overall in their personal caregiving is one of their other children, i.e. a sibling of the deceased child. This occurred in just over half of cases in which the parent provided any care and almost as frequently in cases in which a parent was a main caregiver. Sisters (i.e. daughters of the AIDS parents) helped the parent almost twice as commonly as brothers in personal caregiving. In contrast, children of the deceased were rarely helped as caregivers, reflecting both the fact most deceased adult children did not have any children of their own and that the children they did have were too young to give care.

Spouses of the deceased helped in almost 30 percent of cases in which a parent gave any personal care and in just over a fifth of cases in which a parent was a main caregiver. If conditioned on the deceased child being currently married at the time of death, spouses contributed personal care together with the AIDS parents in two-thirds of the cases and thus were the most common person to share personal caregiving with an AIDS parent among this subset of cases (results not shown). A clear gender difference is apparent, however, with 74 percent of wives of deceased sons sharing personal care with the parent compared to 43 percent of husbands of deceased daughters doing so (results not shown). Indeed the results in Table 7 indicate similar gender differences are apparent for all categories of persons who shared personal caregiving with AIDS parents.

As with personal caregiving, siblings of the deceased were also the most common persons to share in providing instrumental help along with an AIDS parent, doing so in two-fifths of all cases where a parent was also responsible for instrumental help and in 30 percent of cases in which a parent was the main provider of instrumental assistance. However, in this case, brothers and sisters were about equally common in doing so. Spouses also assisted frequently. For married deceased children, a spouse helped in just over half of the cases (results not shown). Again a gender difference is apparent, with wives more commonly helping parents who lost a son than husbands helping parents who lost a daughter (results not shown).

The open-ended interviews make clear that the substantial physical, emotional, financial and time demands created by AIDS caregiving made it difficult for those who assumed primary responsibility to cope with everything on their own. One common response was to solicit help from others within the family. The stigmatized nature of AIDS often reinforced the tendency of parental caregivers to limit the call for help to within their own immediate family. However, given the nature of much of the needs

involved, the family would in any case be the likely source where help would be sought or offered regardless of any stigma.

The open-ended interviews also revealed considerable diversity in the family assistance provided a parental caregiver. It could range from more or less equal sharing of the tasks between both parents or between a mother and a daughter-in-law to occasional help from other family members for a specific type of task. In some cases, the spouse or sibling of the ill person was the primary caregiver and the parent was the one to play more of a supportive role. Some assistance provided to older parents in their caregiving was of an occasional and specialized nature such as help with lifting or moving the ill adult child or providing transport to a health facility. Except for health workers who provided care during hospital stays, few non-family members seemed to have been involved in caregiving in any substantial sense in the cases we interviewed.

Economic support of adult children with AIDS

Parents not only provide care for their AIDS stricken adult children but also often shoulder much of the expenses associated with care and treatment and the eventual funeral. The key informant study asked about economic support only for cases for which supplemental information was solicited. For these cases the informant reported if there had been substantial expenses for treatment and medicines for the PHA and, if so, who paid for the expenses. The top panel of table 8 shows the results both for all cases with supplemental information and conditioned on having at least one parent known to be alive at the time of illness.¹⁸ For over two-fifths (43%) of all cases, the informant reported that parents had helped with the expenses and had been the sole source of payment in almost a third (31%). For cases in which a parent was known to be alive at the time of illness, parents helped with expenses over half (52%) of the time and were the sole source in close to two fifths (37%). The parental role of paying for treatment and medicine is strongly related to the parents role in caregiving. Being main caregivers doubled their chances of helping cover the expenses and made it three and half times more likely to have been the sole source of payment. The economic status of the parents, however, does not show a consistent relationship to the role of parents paying for the expenses of treatment and medicine. Although the lowest involvement is among poor parents, the greater involvement by parents in the middle category compared to those who were either the better off or poor is more pronounced.

[Table 8 about here]

The direct interview survey asked AIDS parents to provide considerable detail about the expenses they incurred in connection with the care and treatment of their deceased adult child. Results are shown in the second panel of table 8. Because the direct interview sample is skewed towards cases in which the deceased child lived near or with parents at the terminal stage of illness, the results for the overall sample overstate the level of involvement compared to what would be found for a more representative sample. As noted above, however, there is less reason to believe that the AIDS parents interviewed who were involved in caregiving are necessarily atypical of this substantial subgroup. Moreover, although the levels indicated for the different economic status groupings may be inflated, there is no obvious reason why the pattern of differentials would be distorted.

¹⁸ For 5-6 percent of the cases the key informant reported that there were no substantial expenses for treatment and medicine for the person who died of AIDS. This included both cases in which there was little treatment and those for which all or most of the expenses were covered by insurance or welfare. These cases are included in the denominator when calculating the percentages shown in the table.

Among the direct interview survey sample, parents helped pay expenses for treatment and care during the period of illness for a very high percentage of adult children who died of AIDS (82% of the cases) and in over three-fifths (61%) they contributed a substantial amount (defined as 5000 Baht or over).¹⁹ For over three-fifths (63%) of the cases, a parent was a main contributor to expenses during the period of the child's illness. Similar to findings from the key informant study, in situations where a parent served as a main personal caregiver, parental involvement in expenses is substantially higher than in cases in which the parents did not take on a main caregiving role. Economic status is also related to involvement in paying expenses for care and treatment. Compared to those of average or better off economic status, poorer parents were noticeably less likely to contribute to expenses and particularly less likely to pay a substantial amount or to be a main contributor.

Results from the direct interview survey also indicate the percent of cases in which parents helped pay for specific expenses associated with care and treatment. The most common expense was for food. In addition, in the majority of cases parents also helped pay for medicine, medical services including hospital fees, and transportation (presumably to health facilities). Among those cases in which a parent was a main personal caregiver, parents were noticeably more likely to contribute to these types of expenses than among cases in which a parent did not serve as a main caregiver. Consistent with overall levels of involvement in expenses, poor economic status is associated with lower percentages of cases in which parents contributed to each of these aspects of care and treatment.

Comparisons in the levels of involvement revealed by the two different sources are difficult because of differences in the questions asked. However, if we consider contributing to medicine, medical services, or hospital fees equivalent to paying for treatment, we can derive a measure from the direct interview survey by combining those categories that are roughly comparable to the measure in the key informant study. The result indicates that 64 percent reported to have contributed to such expenses in the direct interview survey, a figure that is substantially higher than the 52 percent from the key informant study, probably reflecting the expected upward bias in parental involvement in the direct interview survey. However, if consideration is limited to cases in which a parent was a main caregiver, the key informant study percentage of 63 is reasonably close to the equivalent result of 69 percent from the direct interview survey, especially when some allowance is made for the fact the question in the key informant study refers to 'substantial' expenses rather than any expenses. This conforms with our belief that the direct interview survey yields relatively unbiased results for the large group of AIDS parents who become involved in the care of their ill son or daughter.

Parental involvement in paying funeral expenses based on the direct interview survey are also shown in table 8. Funerals usually are major social events in Thailand. They typically last at least several days and involve treating guests to refreshments or meals. The burden of paying for a funeral in Thailand is commonly mitigated by the customary practice of making monetary contributions towards expenses by those attending. Also many families belong to local funeral societies which serve as a form of insurance (Im-em and Suwannarat 2002). In return for making regular payments, a member receives a lump sum benefit when a death in the family occurs. In some cases, funeral costs can be fully compensated by some combination of contributions of those attending, funeral society benefits, and welfare relief for the funeral. Nevertheless, most parents incur net costs for the funeral of their deceased adult child. In almost three-fourths (74%) of the cases covered by the direct interview survey, the parents incurred net funeral costs and in over three-fifths (62%) had substantial net costs (5000 Baht or over). Both situations were less common for cases in which a parent was not a main care provider. This may reflect a greater availability of others besides a parent to cover the funeral expenses in such cases as indicated by the fact

¹⁹ At the time of the survey, the exchange rate for the Baht ranged from 35-40 Baht = \$1 (US).

others were also available to provide main care. Poorer parents were somewhat less likely than better off ones to have a net cost, particularly a substantial one.

As with caregiving, parents who pay expenses for their child with AIDS sometimes receive help from other family members who in some cases are actually bearing the main brunt of the costs. Although the key informant study indicated that parents were more likely to be the sole source of support rather than to be joined by (or join) other family members in this, key informants may not be fully aware of the intra-familial dynamics that took place in connection with covering the expenses. Even when parents are main contributors to expenses, others may provide some contributions. Table 9 indicates, based on the direct interview survey, the percent of different family members and other persons who contributed to expenses in relation to the role played by the parent. The survey did not include a question of who paid for the funeral besides the parents so the following discussion does not take funeral expenses into account.

[Table 9 about here]

Overall, in over half (53%) of the cases in which a parent was a main contributor to care and treatment expenses, others also shared the costs. Whether or not a parent was a main contributor, siblings of the deceased adult child (i.e. other children of the AIDS parents) stand out as being particularly important in helping. Among siblings, sisters contributed to expenses more commonly than brothers. The adult child who died also contributed to his or her own expenses. In over two-fifths (41%) of the cases where a parent was not a main contributor, the deceased child helped pay for expenses and was the main contributor in over a third (36%). Spouses of the deceased adult child also made contributions to expenses in a number of cases. Among cases of deceased adult children who were currently married at the time of death, spouses helped in almost half of the cases when a parent was not a main contributor to expenses and in almost a third when the parents was a main contributor (results not shown in table).

The open ended interviews are quite consistent with the quantitative results. They reveal considerable diversity in the combination of sources drawn on to cover expenses associated with the illness and death of their son or daughter. Most prominent in the accounts of who else helped were the other children of the respondent. However, in most cases it was clear that whatever the combination, parents were typically an important part of it if not necessarily the only source.

I had to buy AZT. It's about 3-4,000 Baht a month, later 6-7,000 Baht a month. I had to pay from my own pocket. I borrowed money other people, too. His father gave me 20,000 Baht... I did whatever I could. I also went to get supplementary food from the temple... I can tell you with no shame that I sold all the jewelry that I had.

[51 year old mother, middle income, Bangkok]

Interviewer: Who paid for all the expenses while your son was sick?

Mother: We did. If we didn't have enough money, we borrowed from our relatives. His brothers and sisters also helped.

Interviewer: Were there a lot of expenses for the funeral?

Mother: It was more than 40,000 Baht. We had to pay for the food for the guests and everything. We are members of the funeral society... We also got money from donations. After the funeral, we were 7-8,000 Baht in debt. Our relatives helped us.

[67 year old mother, poor, Chiang Mai]

We all helped with his expenses, his older brothers and sisters, my husband... It's something that we had to pay because he's our responsibility. Even if we didn't have any money, we would have borrowed from somewhere else for his treatment... But he had several brothers and

sisters to help... They never said that they were in difficulties. They only wanted their brother to get well and survive.

[61 year old mother, poor, Phetchaburi]

Interviewer: Where did you get the money (to pay for treatment and care costs)?

Mother: I had the money. I made desserts. I had my savings. When my daughter was at the hospital, I had about 100,000 Baht. When she was sick, I withdrew 40,000 Baht from the bank... I never borrowed from anyone. I'm afraid that they wouldn't give the money to me. I sold my gold.

[57 year old mother, middle income, Rayong]

Care and support of AIDS orphans

Besides providing care and support to their AIDS infected adult sons or daughters, AIDS parents may also take responsibility for the dependents, particularly the grandchildren left behind. Such children are typically referred to as AIDS orphans even though they may still have one surviving parent. In Thailand, a substantial share of adults who die of AIDS are still single and a fair share of those who are married do not have any living children. For example, among adults who died of AIDS as reported in the key informant study, a third were single and over a third of those who had been married had no dependent children. Thus only 42 percent left behind dependent children. Results from the direct interview survey are similar indicating that 44 percent of those who died of AIDS left no children behind.²⁰ However, among cases where the adult son or daughter did have a child, grandparents often become involved in their care and support.

For the subset of cases about whom supplemental information was solicited in the key informant study, we asked who cared for the dependent children of the person who died of AIDS. Table 10 indicates the person who took responsibility. 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.²¹ Since we are particularly interested in the role of older parents of the adult who died, results are also shown conditioned on the person who died having a living parent.

[Table 10 about here]

The most common person to care for the dependent child of persons who died of AIDS is the their spouse (the dependent child's surviving parent). This occurred in about half of the cases. Parents and parents-in-law (i.e. the grandparents of the dependent child) also are common care takers of AIDS orphans. In over

²⁰ The two figures are not exactly comparable. In the key informant study we asked about 'dependent' children specifying a cut off age of 15 although it is not clear how strictly this age limit was taken into consideration. Presumably a modest number of the persons who died had only children over the age 15 and some of these would have been reported as having no dependent children. In the direct interview survey, we asked about all children of the deceased adult child. In 7 percent of the cases who had any living children, all the children were aged over 15. Thus, if these case are excluded, 41 percent of the deceased son and daughters had children aged 15 or younger.

²¹ Multiple caregiving arrangements would also arise if the person who died of AIDS had more than one child and different persons took responsibility for different sibs. This situation, however, is likely rare, both because most of those who die have at most only one dependent child and because a sibship is probably unlikely to be split up. For example, according to the direct interview survey, 72 percent of the deceased adult child who left a child behind, left only a single child. A 'case' in Table 10 therefore corresponds mainly to the collective sibship of children left behind by a person dying of AIDS.

a third of cases where the adults who died had a living parent, their parent took care of the grandchild. Parents-in-law also played a role, providing foster care in 16 percent of cases overall. Some significant proportion of surviving spouses of persons who died of AIDS, however, are themselves infected by HIV and are likely to die before the dependent child grows up. In many such cases, grandparents are likely to take over responsibility for the orphans. This is indicated by the fact that in 80 percent of the 20 cases in which the person who died of AIDS had a dependent child but no spouse at the time of death (but had a living parent), parents or parents-in-law of the person who died cared for the orphaned grandchildren (results not shown). Thus the percentage of cases in which grandparents will eventually take care of AIDS orphans is certain to be substantially higher than observed at the time of data collection.

Table 11 provides information from the direct interview survey on the children of persons who died. Of the children left behind, more than half (55 percent) are known to have a surviving parent, the large majority of whom is the mother. Approximately 55 percent of the orphans had ever lived with a parent of the parent who died. This differs, however, according to whether or not the other parent of the child was still alive, reaching two thirds of cases in which both parents are dead. Also, for children with a surviving parent, the child is more likely to live with maternal grandparents if that parent is the father than they are to live with paternal grandparents if the surviving parent is the mother. Over two-fifths of AIDS orphans are currently living with the grandparents whose adult child died (the orphan's father or mother). Again this is considerably higher, reaching 56 percent, if both of the orphans parents are known dead. In cases where at least one parent survives, the child is most likely to still live with that parent if the surviving parent is the mother but not if the surviving parent is the father. A substantial number of AIDS orphans also live with the parents-in-law of the parent who died, especially if neither of their own parents are surviving.

[Table 11 about here]

Caution is needed in interpreting the level of grandparental fostering indicated by the direct interview survey given a likely bias towards grandparental involvement. Our open-ended interviews suggest that the circumstances that lead to grandparental fostering of AIDS orphans are likely linked with the living and caregiving arrangements of the adult children with AIDS at the terminal stage of illness. AIDS parents who act as main caregivers to their ill adult child or who co-resided with or lived nearby (including cases in which the adult child returned to the parental home during the illness) are likely to inherit the responsibility for the ill child's offspring. Since the selection of cases in the direct interview survey is biased towards AIDS parents who lived with or nearby their deceased son or daughter and who provided care for them, they would be particularly prone to fostering orphaned grandchildren. On the other had, as noted above, some additional grandchildren are likely to pass to the grandparents when the surviving parent dies of AIDS.

Our open-ended interviews also revealed that there is a considerable range in the willingness and determination with which grandparents assume their role as foster parents of AIDS orphans. Some grandparents are determined even before the impending death of their son or daughter to take on the responsibility. Others appear to inherit the responsibility in an unplanned fashion, more a result of circumstances not under their control than anything else, and in still others the fostering of the grandchild is done only reluctantly. Grandparents may take charge of the grandchild even when there is a surviving parent and even when that parent is not HIV positive. This can arise either because the grandparents do not want to let the grandchild go or because the surviving parent does not want to be burdened by the child. In cases where the spouse of a co-resident ill child has already died or where the spouse deserted or does not want the children, fostering will almost automatically go to the parents of the deceased adult child. Such cases could force parents to take the responsibility for the grandchildren even if they are in financial difficulties. In other cases, fostering may be shared if the ill child's spouse is still alive and continues to co-reside with parents-in-law.

Our interviews also suggest that determination and willingness to foster the grandchild is likely conditioned by the grandparents' financial status. Grandparents who are well off appear to be more likely to foster willingly. For poor grandparents, fostering the grandchild may result because there is no other viable option, even if they not eager to take on the responsibility.

Conclusions

The AIDS epidemic in Thailand, as in other countries with significant numbers of persons with HIV/AIDS, has created a major need for health care and material and emotional support for those infected and their families. The challenge these needs pose for the Thai government has been exacerbated in recent years by the serious economic crisis in the country that started in 1997 and is still awaiting full recovery five years later. This period of economic difficulty unfortunately coincides with a period when symptomatic AIDS cases are reaching their highest level (Thai Working Group on HIV/AIDS Projection 2001). Despite this crisis, however, the Thai Government has continued to make available extensive basic health insurance that has provided considerable financial relief to many PHAs and their families by covering some or most of their medical costs (but not expensive anti-retroviral treatments although this may change in the future). Long term care for PHAs, however, is largely not the norm at government hospitals nor at most of the few NGO hospices. The government, and to some extent NGOs, have also provided some limited material support through various AIDS related welfare and assistance programs, especially in the hard hit upper north region. Nevertheless, only a minority of PHAs or their families receive such assistance and those who do typically receive rather modest amounts that are unlikely to cover more than the barest subsistence needs.

Compared to many of the poorest African countries where the AIDS epidemic is far worse, formal health and welfare assistance to PHAs and their families are probably far better in Thailand. Yet this formal safety net still leaves the bulk of care and support to be found outside such organized efforts. Under these circumstances it is not surprising that in Thailand older age parents typically play a central role in caring for and supporting their adult sons and daughters when then become seriously ill with AIDS. Mothers are especially important in giving personal care at the terminal stage. For married PHAs, surviving spouses, especially wives, often play a major role. In many cases other family members, especially non-infected adult siblings of the PHA assist in specific ways. The fact that more than half of PHAs in Thailand eventually end up living with nearby parents at the terminal stage of their illness and that parents commonly provide care and support to their AIDS afflicted adult sons and daughters testifies to older age parents as the final and most important safety net in the context of the Thai AIDS epidemic.

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Appendix. Welfare programs related to AIDS

As a result of the national policy on AIDS, welfare for people with HIV/AIDS has received some emphasis recently in governmental policy and programs. Several different departments in the Ministry of Labor Force and Social Welfare are responsible for assisting people with HIV/AIDS and their families. As a result various type of welfare have become available. They all require that applications be made in the jurisdiction where their recipients household is registered. In addition, medical certification must be provided as proof of HIV/AIDS.

1. Monthly allowances for people with AIDS until death. The amount of the allowance is 500 Baht a month and its purpose is to support poor or deserted PHAs who are unable to earn their living and to assist them to live normally with their family within the local community. One additional requirement is that the PHA be medically certified as already having reached the symptomatic stage of HIV/AIDS.

2. Subsidies for women who either are infected or affected by HIV/AIDS. Eligible women receive a one time payment of 5000 Baht. The program targets various types of women including infected former commercial sex workers; infected women who are heads of households with dependents; infected women who have no means of support; non-infected women who are heads of households with an infected dependent; women whose husband is infected or died of AIDS and has dependents. Dependents include co-resident husband, children, parents or parents-in-law, and other relatives who have been supported by the woman for at least 3 months.

3. Subsidies for people with HIV/AIDS and their family. Eligible applicants receive up to 2000 Baht in cash or kind at a time up to three times. The program targets infected household heads with dependents; non-infected household head households with an infected dependent; families whose head died of AIDS; infected persons who have no means of support. The program provides food or cash. Payments are intended to help with living expenses, medical costs, transportation connected with hospitalization or medical services, expenses for fixing the house, for earning the living, and other needs.

4. Subsidies for HIV/AIDS infected laborers. The program targets laborers provides up to 20,000 Baht for job training and related expenses; to start a business; for education of dependent children; and miscellaneous expenses incurred by the infected person and his/her family.

5. Welfare for children of PHAs. This program provides a one time payment of 1000 Baht per child up to 3000 Baht per family in which a parent is HIV infected or has died of AIDS or a child is HIV infected. The aims is to help children within these families in their living expense and for their education. In some cases payment is in kind consisting of food or clothes.

Table 1. HIV prevalence indicator and number of cases by source of data and province

Province	% HIV positive among military recruits, 1991-2000	Key Informant Study (adult cases for which information was reported)	Direct Interview Survey with AIDS parents	Open ended interviews with AIDS parents
Total	--	1032	394	20
Chiang Mai	6.48	173	153	6
Rayong	4.23	230	137	8
Phichit	1.51	96	104	
Chiang Rai	7.60	167		
Khon Kaen	1.14	62		
Phetchaburi	3.30	104		3
Phuket	3.78	74		
Ubon Ratchatani	1.15	75		
Bangkok	1.90	51		3

Table 2. Health insurance and welfare assistance for adults who died of AIDS, by economic status of the person with AIDS and economic status of parents

	Total (a)	Economic status before illness		
		Good	Average	Poor
% for whom insurance was mentioned as helping cover expenses for treatment and medicine				
By economic status of person with AIDS	51.5	30.0	54.1	60.0
By economic status of parents of person with AIDS	51.5	43.6	50.0	55.6
% who received welfare funds (for self or family)				
By economic status of person with AIDS	21.1	13.6	13.7	31.6
By economic status of parents of person with AIDS	21.1	13.6	18.8	30.8

Notes: (a) includes all cases regardless of missing information on economic status or living status of parents.

Source: key informant study

Table 3. Health insurance and welfare assistance received by adult children who died of AIDS and their families, by parents' role in contributing to care expenses and economic status

	All cases	Economic status		
		Better off	Average	Poorer
N of cases	394	75	131	187
Health insurance				
<i>% of cases in which health insurance helped paid for medical costs</i>	59.6	50.7	62.0	62.0
Among cases for whom insurance helped pay medical expenses:				
<i>Type of insurance used (% distribution)</i>				
government health card (purchased)	50.4	47.4	60.0	44.7
welfare card	22.0	7.9	15.0	31.6
civil service/social security system	12.9	34.2	10.0	7.9
private	0.9	0.0	1.3	0.9
other	13.8	10.5	13.8	14.9
total percent	100	100	100	100
<i>Extent to which insurance helped with expenses (% distribution)</i>				
very much	55.7	48.6	52.6	60.2
some	34.6	37.8	41.0	29.2
not much	9.6	13.5	6.4	10.6
total percent	100	100	100	100
AIDS Welfare assistance (a)				
<i>% of cases that received welfare payments</i>	18.8	14.9	14.0	23.9
Among cases who received welfare:				
<i>Duration of payments (% distribution)</i>				
1 month or less	41.2	**	44.4	33.3
2-5 months	17.6	**	5.6	21.4
6+ months	20.6	**	38.9	16.7
family still receives payments	20.6	**	11.1	28.6
total percent	100	**	100	100
<i>Amount received</i>				
mean	10342	3818	22416	7189
median	4000	4000	6000	3850
<i>Extent to which welfare helped with expenses (% distribution)</i>				
very much	19.1	9.1	13.3	23.8
some	35.3	9.1	60.0	33.3
not much	45.6	81.8	26.7	42.9
total percent	100	100	100	100

Notes: (a) Welfare payments include assistance from NGOs.

** = less than 10 cases.

Source: Direct interview survey.

Table 4. Parental caregivers and instrumental helpers by gender

	Percent distribution (cases in which at least one parent provided the type of assistance specified)				Ratio of mother to father (a)
	Mother only	Father only	Both parents	Total percent	
All cases of assistance (including widows and widowers)					
<i>Key informant study</i>					
Any personal care	48.5	8.6	42.9	100	1.8
Main personal caregiver	70.0	9.8	20.2	100	3.0
<i>Direct interview survey</i>					
Any personal care	37.6	8.1	54.3	100	1.5
Main personal caregiver	72.6	15.3	12.1	100	3.1
Any instrumental help	39.1	24.6	36.3	100	1.2
Main instrumental helper	58.9	34.1	7.0	100	1.6
Cases of assistance in which both parents were alive					
<i>Direct interview survey</i>					
Any personal care	22.3	4.7	73.0	100	1.2
Main personal caregiver	70.0	15.0	15.0	100	2.8
Any instrumental help	25.5	27.4	47.1	100	1.0
Main instrumental helper	51.6	40.4	8.1	100	1.2

Table 5. Parental caregiving duration by return migration status of adult child who died of AIDS

	All cases	Return migration status	
		In parental locality before onset of symptoms	Returned to parental locality following onset of symptoms
Percent distribution of caregiving duration			
Less than 1 month	33.3	32.4	35.4
1-2 months	35.0	34.0	37.2
3-5 months	17.2	16.6	18.6
6-11 months	7.3	9.5	2.7
1 year or longer	7.1	7.5	6.2
Mean	2.9	3.1	2.5
Median	1.0	2.0	1.0
Number of cases	354	241	113

Source: Direct interview survey.

Table 6. Percent of parents performing specific tasks of personal caregiving and instrumental help among parents who assisted their adult child with AIDS by performing at least one activity

	Total	Which parent provided assistance		
		Mother only	Father only	Both parents
Type of activity				
Watching over	91.3	91.1	83.9	92.4
Preparing food	85.5	86.3	58.1	89.1
Shopping for food	78.3	80.5	58.1	80.0
Providing transportation, e.g. to clinic or hospital	74.7	67.2	58.1	81.5
Lifting and moving	72.4	68.5	54.8	77.3
Preparing and giving medicine	72.1	72.6	61.3	73.5
Feeding	67.8	66.1	51.6	71.1
Helping with toilet; changing soiled linens	66.9	63.7	41.9	72.5
Cleaning, laundry, doing dishes	66.8	71.0	32.3	69.5
Consulting with health care providers	65.1	65.9	38.7	68.6
Bathing	62.3	61.3	35.5	66.8
Dressing	60.7	62.9	38.7	62.6
Helping apply for welfare benefits	22.9	20.3	12.9	25.8
Arranging legal and financial affairs	16.9	14.8	22.6	17.3
Cleaning wounds	16.5	14.8	16.1	17.6
N of cases	366	124	31	211

Note: Excludes cases in which a parent did not provide either personal care or instrumental help.

Table 7. Percent providing personal care or instrumental help in addition to parents, among cases in which parents assisted their adult child with AIDS in the specified type of assistance

Relation to person who died of AIDS	Personal care		Instrumental help	
	Parent gave any care	Parent main caregiver	Parent gave any care	Parent main caregiver
All (a)	68.5	61.6	52.3	42.1
Spouse	28.4	21.0	21.4	16.4
Any child	4.2	4.3	1.8	1.4
Son	2.2	2.5	0.7	0.5
Daughter	2.8	2.5	1.1	0.9
Any sibling	51.0	47.7	39.9	30.2
Brother	21.7	21.4	24.9	20.1
Sister	40.1	37.0	24.2	17.3
Other male	4.5	3.2	7.1	7.0
Other female	6.1	5.0	6.0	5.1
N of cases	359	281	281	214

Notes (a) Includes a small number of persons other than those listed above

Table 8. Involvement of parents in expenses related to care and treatment of adult children who died of AIDS, by caregiving and economic status

	Total cases	Was parent a main personal caregiver?		Economic status (of parents)		
		No	Yes	Better off	Average	Poorer
From key informant study, % of adult children for whom:						
<i>Parents helped pay for treatment and medicine</i>						
all cases including those with no living parent	42.9	n.a.	n.a.	n.a.	n.a.	n.a.
only cases with a known living parent	51.7	32.9	63.5	50.0	59.1	48.1
<i>Parents were sole source of paying for treatment and medicine</i>						
all cases including those with no living parent	31.0	n.a.	n.a.	n.a.	n.a.	n.a.
only cases with a known living parent	37.4	14.3	51.6.	36.4	46.2	29.6
<i>N of cases (a)</i>	245/203	76	126	44	93	54
From direct interview survey, % of adult children for whom:						
<i>A parent helped pay expenses during adult child's illness</i>						
any expenses	81.7	66.4	87.9	86.7	88.5	74.9
substantial expenses (5000+ Baht)	61.0	41.8	68.6	77.0	70.0	47.8
<i>A parent was a main contributor to expenses during adult child's illness</i>	62.6	38.9	72.2	71.6	67.2	55.4
<i>A parent helped pay for:</i>						
medicine	63.4	50.4	68.6	73.3	71.0	53.8
medical services/hospital fees	56.0	45.1	60.4	68.0	67.2	43.0
transportation	66.4	46.9	74.3	74.7	71.0	59.7
food	80.2	61.1	87.9	82.7	88.5	73.1
<i>A parent helped pay for the funeral</i>						
any net cost	74.3	63.6	78.5	76.0	83.1	67.2
substantial net cost (5000+ Baht)	62.0	49.1	67.0	70.7	71.5	51.4
<i>N of cases</i>	394	113	281	75	131	187

Notes: (a) Results for the key informant study refer to the subset of cases with supplemental information. The first number in the total cases column refers to all cases including those with no living parent; the second refers to only cases with a known living parent. The sum of cases in categories under main caregiver status only cases with a known living or economic status do not add to the total because some cases are missing information regarding these characteristics.

Table 9. Percent contributing to payment of treatment and care expenses, by relation to person who died of AIDS and parents' role in covering expenses.

Relation to person who died of AIDS	Parent was not main contributor (a)		Parent was main contributor
	% making any contribution	% making a main contribution	% making any contribution
Self	41.1	35.6	17.6
Spouse	24.0	17.8	13.1
Parent	52.7	0.0	100.0
Any child	0.0	0.0	0.0
Any sibling	54.8	43.2	28.7
Brother	32.2	16.4	13.5
Sister	42.5	32.2	24.2
Other male	4.8	3.4	2.5
Other female	2.7	1.4	1.6
Other, sex unspecified(b)	8.9	5.5	3.3
% of cases in which persons other than a parent contributed	100.0	100.0	52.9
N of cases	150	150	240

Source: Direct interview survey.

Notes: (a) includes cases in which parents did not contribute to paying expenses

(b) Includes place of employment, NGOs, etc.

Table 10. Persons who provided care to dependent children of adults who died of AIDS

	% of adults who died of AIDS whose children were taken care of specific types of relatives	
	All persons who died of AIDS and had a dependent child	Persons who died of AIDS, had a dependent child, and had a living parent when ill
Relation of person providing care to person who died of AIDS		
spouse (i.e. surviving parent of dependent child)	50.8	52.4
parent	31.1	36.2
parent-in-law	15.6	13.3
other (including non-relatives)	10.7	6.7
N	122	105

Note: Percents add to over 100 because for some cases more than one fostering arrangement occurred.

Source: Key informant study (subset of cases with supplemental information)

Table 11. Living arrangements of surviving children of persons who died of AIDS (and whom at least one of whose own parents was alive)

	All orphans	Is a parent still alive?			Among orphans with a surviving parent, sex of parent	
		Yes	No	Not known	Father	Mother
N of cases	253	139	87	27	25	114
% who ever lived with the parent(s) of the parent who died (since the death)	54.9	48.2	66.7	51.9	56.0	46.5
Current living arrangement (% distribution)						
with spouse of person who died (i.e. surviving parent of dependent child) (a)	25.8	39.6	0.0	33.3	24.0	43.0
with parent(s) of the person who died (b)	43.3	36.7	55.8	37.0	56.0	32.5
with parent(s)-in-law of parent who died(b)	14.7	13.7	16.3	14.8	12.0	14.0
other	16.3	10.1	27.9	14.8	8.0	10.5
total percent	100	100	100	100	100	100

Notes: (a) may include some cases in which the surviving parent co-resides with or lives adjacent to their own parents (i.e. the parents-in-law of the parent who died).

(b) includes some cases in which the surviving parent co-resides with or lives adjacent to the parent of the parent who died.

Source: direct interview survey

Figure 1. Living and caregiving arrangements at terminal stage of illness for adults who died of AIDS (source: Key informant study)

