

The Economic Consequences for Parents of Losing an Adult Child to AIDS: Evidence from Thailand

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As the worldwide HIV/AIDS epidemic continues, there is increasing recognition that concern needs to broaden beyond the infected individuals themselves. Non-infected family members and significant others can be affected emotionally, economically, socially, and physically by the illness and death of a person with AIDS. This is particularly true for persons who serve as caregivers. Much attention has been given to AIDS orphans, the children of persons with AIDS. Yet persons with AIDS not only have children but many also have older-age parents who are affected in significant ways and who often act as caregivers to their infected adult children. Despite this, almost no attention has been paid so far to AIDS parents (the term we use to refer to parents who lose a son or daughter to AIDS), other than recognition of their responsibility as grandparents for caring for the AIDS orphans. Their critical role as caregivers to their adult sons and daughters is typically overlooked because research on AIDS caregiving in the developing world is not extensive. Several studies that have been done, however, underscore the importance of the traditional family in providing care and support for adults with AIDS and particularly the major role that parents play (Knodel, VanLandingham, and Watkins forthcoming; Ntozi and Nakayiwa 1999; de Bruyn 1992). The most extensive research so far is from Thailand and indicates that parents, usually the mother, provided care for almost two-thirds of adults who died of AIDS and acted as primary caregivers for half (Knodel, VanLandingham, Saengtienchai, and Im-Em 2001).

Parental caregiving is an important but by no means the only pathway through which the illness and death of an adult child can impact the financial situation and economic well being of AIDS parents. Even parents who do not provide care may still help shoulder treatment and health care expenses during the illness and funeral costs after the death. Negative community reaction may lead to a loss of customers if the parents run a shop or sell products locally. If the deceased child had been contributing to household income or economic activity, or was providing support to parents in other ways, the parents may suffer from the cessation of such support. Moreover, the future economic well being of the parents can also be impacted through the loss of contributions to old age that could have been anticipated had the adult child survived. Finally, parents who take responsibility for orphaned grand children can incur substantial and sustained expenses for many years ahead.¹ Some of these same potential economic consequences would also follow from the illness and death of an adult child from any cause and thus are not unique to AIDS. However, some aspects, such as the duration of the illness, the types of symptoms suffered, and the nature of community reaction, are fairly specific to AIDS. More importantly, in countries in which there is a substantial epidemic, AIDS can be the most important cause of death of adult children of older persons and where prevalence levels are high can account for the majority of parental losses of adult children. For Thailand, for example, where adult prevalence is just 2 percent, microsimulation estimates indicate that the presence of AIDS increases the chance that an older person will lose one or more adult children during their lifetime by 70 percent (Wachter, Knodel, and VanLandingham 2002).

Several efforts have been made to empirically investigate the economic consequences of AIDS for the household in Thailand and elsewhere (Bloom and Lyons 1993);(Pitayanon, Kongsin, and Janjareon 1997; Im-em and Phuongsachai 1999; Kongsin, Jiamton, Watts, and Boonthum 2001). None, however, have focused specifically on the impact for older aged parents. In this paper we examine the economic consequences for parents of losing an adult child to AIDS in Thailand with emphasis on the effects of

¹ See (Knodel et al. forthcoming) for a fuller explication of potential pathways through which the loss of an adult child can impact parents.

parental caregiving. The analysis is based on a combination of quantitative and qualitative data derived from several different data collection approaches. We start with a brief review of the Thai setting before describing the data sources and presenting the results.

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 with AIDS and by the mid-1990s the numbers of deaths were starting to mount in substantial number. 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, these same estimates project that deaths will hover around 50,000 a year for the next decade (Phoolcharoen, Ungchusak, Sittitjai, and Brown 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, VanLandingham, Saengtienchai, and Pramualratana 1996). More recently, infected men are increasingly spreading the virus to their wives and non-commercial partners (Chitwarakorn, Sittitjai, Brown, and Mugrditchian 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 was also experiencing 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 quickly to many other countries in the region (Gragnotati 2001); (United Nations Development Programme (UNDP) 1999). 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. Specific efforts during the crisis targeted the maintenance and even expansion of public low cost health insurance and social welfare programs aimed at the most vulnerable.

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 (United Nations 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 when an adult son or daughter dies of AIDS.

Exchanges of support and services between parents and adult children are pervasive in Thailand as in much of the developing world (Knodel, Chayovan, Graiurapong, and Suraratdecha 2000; World Bank 1994). Widespread norms supporting filial obligations to parents underlie the existing system of intergenerational relations (Knodel, Saengtienchai, and Sittitjai 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 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.²

Health Insurance and Social Welfare. 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, none of the 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. The various programs are intended to address somewhat different situations resulting from someone becoming HIV infected or ill with AIDS or being a family member of someone with HIV/AIDS. The forms of assistance vary and include cash payments and assistance in kind. Payments may be one time, several times, monthly until death, or even continuing assistance to the dependents after the infected person dies. Targets for assistance vary and include infected persons generally, infected or affected women, infected heads of households, infected laborers, and children of infected persons. All programs are intended for poor or indigent cases. In practice, these different programs are flexible in the manner in which they are applied. One group, however, that is not targeted and receive virtually no assistance are the older-aged parents of persons with HIV/AIDS.

In addition to government programs, there are numerous NGOs (non-governmental organizations) that have programs designed to assist persons with AIDS. The actual numbers of cases reached by these programs, however, are far less widespread than those of the government (Im-em and Suwannarat 2002).

Data sources

Our analysis draws on three data sets that have been collected as part of a comprehensive study of the impact of the AIDS epidemic on older persons in Thailand. The sources of data are based on different methodological approaches: interviews with key informants about individual AIDS cases and their families; direct survey interviews AIDS parents; and open-ended interviews with AIDS parents. The first two were designed to yield data suitable for quantitative analysis and the third to yield data suitable for qualitative analysis. A brief description of each source follows. Detailed accounts of the methodology involved in each component are available elsewhere (Knodel, Saengtienchai, Im-em, and VanLandingham 2000; Saengtienchai and Knodel 2001; Knodel, Im-em, Saengtienchai, VanLandingham, and Kespichayawattana Forthcoming). Information collected in all components was anonymous to protect confidentiality. Table 1 indicates the provinces represented, their HIV prevalence as reflected in tests of military recruits, and the number of cases by each data source.

[Table 1 about here]

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 were paid staff or volunteers associated with local health centers. Interviews took place during 1999 in 85 sites in rural and

² The statistics cited are from original tabulations based on the Survey of Welfare of Elderly in Thailand (Chayovan and Knodel 1997).

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 supplemental questions about the role of the parents in caregiving, who paid the expenses of treatments, the extent to which the expenses were a financial burden, whether or not assets had to be sold to cover expenses, if economic activity was interrupted as a result of caregiving, if extra work had to be taken on to cover expenses, whether welfare payments were received, if the parents were involved in foster care of orphaned grand children, and if the parents' economic situation changed as a result of the adult child's illness. For reasons explained below, we limit our present analysis to the 768 cases of adults who died locally including 258 for whom supplemental information was also collected.

Direct interview survey. In three provinces that were included in the key informant study, we administered a detailed structured questionnaire directly to parents who lost at least one adult child to AIDS, usually within the prior three years and to a comparison group of parents of similar ages and backgrounds from the same survey who had not experienced the recent loss of an adult child. The survey took place during 2000. In two provinces (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 and 376 interviews with comparison cases. 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 AIDS parents (363 mothers and 286 fathers) and 621 comparison parents (345 mothers and 276 fathers).

In addition to covering the same issues as addressed in the key informant study, the direct interview survey provides detailed information on the costs associated with treatment, assistance to dependents of the person with AIDS, and the funeral and formal and informal sources of covering these expenses. The direct interview survey also permits a number of comparisons to be made between AIDS parents and control group parents from which the impact of losing an adult child to AIDS can be inferred.

Local health personnel served as intermediaries in identifying cases of AIDS parents and comparison parents to interview. We eliminated a small number of AIDS parents from consideration whom the intermediary believed would be unwilling to be interviewed. In order to make the actual interviews with AIDS parents less sensitive, the questionnaire did not refer to AIDS as the cause of their child's death. In most sites, the large majority of AIDS parents who were initially identified agreed to be interviewed and most admitted during the interview that their deceased son or daughter had AIDS.³

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. Efforts to collect accurate and representative information about parents of persons with AIDS face imposing methodological challenges. Any practical approach is likely to have serious limitations and/or be prone to some type of bias. The three approaches described above are no exception. The open-ended interviews are based on a small number of cases and thus are only illustrative. While both the key informant study and the direct interview survey provide sufficient cases for quantitative analysis, neither is based on a probability sample and thus can results can not be generalized in any rigorous fashion. Nevertheless, we believe that our multi-method approach can provide considerable insight into the economic impact on parents of losing an adult child to AIDS.

³ For reasons that vary with the particular provincial site, calculating an exact overall response rate is not possible (see (Knodel et al. Forthcoming). However, the information that is available indicates that non-response (for all reasons combined) among cases identified as AIDS parents was under 10 percent.

The key informant study and the direct interview survey have complimentary strengths and weaknesses. All information from the key informant study about the person with AIDS 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 all adults in the local community who were currently symptomatic or who had died of AIDS regardless of whether the parents were alive or dead or where parents 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 with some confidence 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 necessary 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 adult children who returned to the parental community during the illness).

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%) for which a parents 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 economic consequences among the large group of parents who were involved in providing care to their ill adult child. 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 and VanLandingham 2001). All three distributions indicate that the vast majority of AIDS parents are at least age 50 and approximately half are 60 or older. Thus in terms of age, our approaches appear to be covering fairly typical cases. The AIDS cases reported by the key informants and those covered in the direct interview survey also resemble fairly closely 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 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 (see below). Thus the extent of parental involvement in caregiving and other support during their child's 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. Moreover, some potential long term economic impacts on parents such as loss of old age support may not be evident until many years after the death. Thus only a partial accounting of economic impacts on parents can be assessed from our data sources.

In interpreting the quantitative results presented below, it is useful to recognize that the unit 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 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 in those cases when more than one died of AIDS), there is a direct correspondence between AIDS parents and adult children as units of analysis and in this sense the two are interchangeable as 'cases'.⁴ More generally, results in the tables are sometimes conditioned on subsets of cases and thus are based on different numbers of cases.⁵

Results

Caregiving and living arrangements

Older Thais are extensively involved with their infected adult children through both living and caregiving arrangements. This in turn has important implications for the extent to which they contribute to the expenses associated with treatment and care. Figure 1 presents results from the key informant study which, for the reasons explained above, we believe are reasonably representative of a broad range of AIDS parents. The majority of adults who died of AIDS (59%) co-resided with a parent at the terminal stage of their illness and fully two-thirds either co-resided with or lived next to a parent. Moreover, parents assisted in personal caregiving for almost two-thirds of adults who died of AIDS and were main caregivers for half.⁶ If consideration is limited to adults who had at least one living parent, the results are even more striking. For example, coresidence at the terminal stage rises to almost 70 percent and for almost 60 percent a parent was a main caregiver.⁷

[Figure 1 about here]

In understanding the high prevalence of parental terminal stage caregiving to adults with AIDS in Thailand, it is useful to recognize that there are two basic routes that lead to the situation. In some cases the son or daughter is already living with or near the parents even before becoming ill; in others, the adult child lived elsewhere when symptoms first appear but returned to the parental community after becoming ill. Both routes are substantial. 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

⁴ 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.

⁵ 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.

⁶ 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. For example, in the direct interview survey, in which up to two persons could be designated as a main caregiver, in 12 percent of the cases where at least one parent was so considered the other parent was also designated as a main caregiver; in 16 percent a parent shared the role with someone other than his or her spouse; in the remaining 72 percent, a parent was considered the sole main caregiver.

⁷ 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).

proximity obviously promotes parental involvement should the son or daughter fall ill. At the same time, substantial return migration of seriously ill adult children, especially in cases of a fatal and incurable disease such as AIDS, is frequent in the Thai context. According to the key informant study, 40 percent of adult children who were cared for by parents at the terminal stage had returned home from elsewhere compared to just under a third (32%) of cases in the direct interview survey. Although the reasons for the difference between the two studies is not obvious, both indicate that return migrants constitute a substantial share of the adult children with AIDS for whom parents provided care during the terminal stage of illness.⁸

The direct interview survey makes clear that in many cases, adult children with AIDS who return to their parents do so at an advanced stage of the illness. Almost one fifth (19%) die within less than a month and 46 percent die within three months. The key informant study agrees well with this indicating that 47 percent of adult children who died of AIDS and lived with and were cared for by their parents died within 'a few' months. On average, the period of serious debilitating illness is no more than a couple of months regardless of migration status. According to the direct interview survey, the mean period of serious illness lasted 1.7 months with only one fourth of the deceased adult children being seriously ill for more than 2 months. Thus it is not surprising that the mean duration of parental caregiving is also only a matter of a few months. Again, according the direct interview survey, the mean period of parental caregiving overall was 2.9 months, although it was modestly longer for those who were living locally before becoming ill (3.1 months) compared to the return migrants (2.5 months). Only in less than a fifth of the cases was care given 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 very emotionally and physically draining for both parent and child.

Care and Treatment Expenses

Illness and death from AIDS can involve a whole array of expenses associated with care and treatment. If parents are involved in covering these expenses, or divert substantial time away from income generating activities in order to give care, they may experience immediate and possibly longer term effects on their financial well being. 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. In addition, the survey explored the ways AIDS parents met these and other expenses. Some information is also available from the subset of cases for which we asked supplemental questions in the key informant study.

Results in table 2 indicate various dimensions of parental involvement in the expenses related to the care and treatment of an adult child who died of AIDS. Results are shown according to the role played by parents as personal caregivers as well as their economic status.⁹ Because the direct interview sample is

⁸ For a fuller discussion of return AIDS migration and the methodological problems associated with estimating rates of return see (Knodel and VanLandingham 2001).

⁹ The measure of household economic status is based on two items in the direct interview survey: 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 house. 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.

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 results concerning AIDS parents who were involved in caregiving are particularly atypical of this substantial subgroup. Moreover, although the levels indicated for the different economic status groupings may be inflated, there is no obvious reason to expect that the pattern of the relationship with economic status is distorted.

[Table 2 about here]

Among our sample of cases, 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).¹⁰ For over three-fifths (63%) of the cases, a parent was a main contributor to expenses during the period of the child's illness.¹¹ 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 in table 2 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 personal caregiver, the percent in which a parent was contributing to these types of expenses is noticeably higher 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.

Questions asked in the key informant study about parents' contributions to expenses were somewhat different and thus only a rough comparison is possible with the direct interview survey results. The key informants were asked if the treatment expenses had been substantial for the person with AIDS and/or his or her family and, if so, who paid for the expenses. In just over half (52%) of cases in which the person who died had living parents, the parents either were the only persons paying the expenses or shared expenses with others (results in this and following paragraph not shown in table).

If we consider contributing to medicine, medical services, or hospital fees equivalent to paying for treatment, we can derive a roughly comparable measure from the direct interview survey by combining those categories. 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 in the key informant study, the percentage who contributed to treatment expenses rises to 63 percent and thus 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

¹⁰ At the time of the survey, the exchange rate for the Baht ranged from 35-40 Baht = \$1 (US).

¹¹ As in the case of the main role in caregiving, respondents could state up to two persons as main contributors to care and treatment expenses. In 9 percent of the cases in which parent was a main contributor, this role was shared with someone else.

relatively unbiased results for the large group of AIDS parents who become involved in the care of their ill son or daughter.

We asked respondents to tell us the total amount they spent for care and treatment.¹² Table 2 includes these results. The distributions of the amount stated were typically skewed and thus we present both mean and median values. Although there are substantial difference between the mean and median values, the patterns of association with the caregiving role of parents and economic status are usually quite similar. Both mean and median values indicate that when a parent was a main personal caregiver, the parents incurred greater costs associated with caring treatment than when a parent was not a main caregiver. However if we limit consideration to parents who were main contributors to expenses, then the relationship between the amount spent on caring treatment is inconsistent and depends on which measure, the mean or the median, is examined. A clear association between the amount parents paid for care and treatment and economic status is evident. This is so whether or not we limit consideration to only cases in which a parent was a main contributor to expenses. The amount spent for care and treatment is thus in part a function of the ability to pay.

Qualitative analysis of the 20 in-depth interviews with AIDS parents yield results that are quite consistent with the quantitative evidence presented so far regarding expenses associated with caregiving and treatment and shed some additional light on how the expenses arose. Increased costs of daily living were mentioned in half of the interviews. One common source of this was buying expensive special foods that would normally not be bought or would otherwise be bought less frequently. In some cases these foods were bought to please the AIDS inflicted person while in others because they were thought to have health benefits. Increased expenses for food also arose in cases where the ill child moved in from elsewhere because food consumption increased.

Interviewer: Did you have to pay a lot of money for him?

Mother: Yes, about 200 Baht a day, because he wanted to eat different kinds of food... We bought anything he wanted. Sometimes he wanted to eat durian (an expensive fruit) so much...

[51 year old mother, Bangkok, Middle Income]

Interviewer: Did you have more expenses during the time he was sick?

Mother: Yes. We paid for clothes that we had to throw away once he used them. We paid for food like meat, desserts, milk, supplementary food, car rental to the hospital. In total, it was more than 1000 Baht a month.

[60 year old mother, Chiang Mai, Poor]

Considerable use was made of the modern health care system for treatment of illnesses suffered by the AIDS-afflicted persons. Doctors' fees, medicines, and hospitalizations could be very substantial. Some of

¹² When asking about this amount (as well as when asking about amounts of money or time regarding other items covered in our questionnaire), we followed a two step strategy. We first asked the respondent to provide a single amount. In cases in which the respondent were unable to estimate a single amount, we probed if the amount was as much as a series of successive amounts. This permitted us to determine if the amount spent was within particular ranges. Most persons could state a single amount (typically rounded) and among those who could not, most could provide an answer to these probes. For example, among those who incurred any expenses for care and treatment, exactly two-thirds were able to state a single amount, 31 percent could provide an answer that placed them within some range, and only 2 percent were unable to state an amount even within the broad ranges in the probe. In order to derive a single estimate for each respondent, we converted answers that were stated in ranges to the midpoint of that range except for respondents who stated the amount paid was above the highest asked in the probe. In those cases, we assigned a value that was equal to the mean of those who stated a single amount that was also above the limit of the highest range.

the better off parents took their ill child to private hospitals where fees were very high. Some parents also bought expensive traditional medicines from outside the modern health system. However, medications could also be expensive in government hospitals, either absolutely or relative to the economic status of the family.

I didn't know whom to turn to. I worried about the expenses for medicines. It cost 100 Baht a pill at the (government) hospital. I had to pay for pain killers... We had to spend both my son's and my own money together.

[65 year old father, Bangkok, Poor]

We paid more than 100,000 Baht. The (private) hospital was very expensive... We paid a lot of money there. When I think of that hospital, I still get goose-bumps.

[54 year old mother and 59 year old father, Phetchaburi, Middle income]

I had to pay a lot each month... Medicines from the hospital didn't stop the symptoms so he took Chinese and other good kinds of (traditional remedies). I paid several thousand Baht a month.

[67 year old mother, Rayong, Well off]

In many cases, however, much of the health care expenses were paid for either through government health insurance or through some welfare measure if the family was poor. This moderated the financial strain imposed on the parents. In at least one case, medicines were purchased from an NGO at subsidized prices.

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, Bangkok, Poor]

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, Rayong, Middle income]

Among the cases we interviewed in-depth, families who paid large sums for health care out of their own pockets were better off financially and more or less could afford it without causing great hardship for them. Many others had some or most of the health care costs covered through government insurance or welfare. 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, were cited as a source of financial hardship that typically lead them to debt.

Opportunity Costs of Caregiving.

Besides direct expenditures, caregiving may require parents to divert time from income generating or other activities of economic value. Table 3 addresses these potential opportunity costs based on the direct interview survey. In almost half of the cases (47%), one or both parents had to either stop or reduce their economic activities. Curtailment of economic activity was over twice as likely for cases in which a parent was a main caregiver than in those in which a parent was not. Also the lower the economic status of the parents, the higher the percentage reducing their work.

[Table 3 about here]

These estimates are considerably higher than ones from the key informant study that indicated reduced economic activities by a parent in 20 percent of cases of adult children who died overall and in 29 percent of cases where a parent played a main caregiving role (results not shown). The difference likely in part reflects the skewed nature of the direct interview survey sample towards parents who were involved in

caregiving. However, it may also reflect a fuller knowledge among AIDS parents themselves about their own activities compared to the key informants.

Among married couples in the direct interview survey, both parents curtailed economic activities in about one-fourth of the cases and in about the same proportion of cases only one parent did. Under the latter circumstances, the mother was more commonly the person to divert time from economic activities than was the father reflecting the far greater tendency for mothers to be main caregivers.¹³

In general, the amount of time in which economic activity was curtailed was relatively short with the median duration being only one month. The distribution of time taken away from economic activities, however, is skewed and thus the mean duration (about three months) is considerably longer. Approximately a third of those who stopped or reduced their work, did so for three months or more. In general, in situations where a parent was a main personal caregiver, the amount of time taken away from economic activities was longer than when no parent served as a main caregiver. The duration of time taken away from normal economic activities does not vary greatly according to economic status.

Respondents were asked to estimate the amount of lost income that resulted from curtailing economic activity. In comparison to the amount spent for care (and funerals -- see below), forgone income is more modest. However, forgone income is substantially more among cases in which a parent served as a main personal caregiver than when a parent did not. Poorer parents indicated the value of time they lost to be less than among those of better economic status, probably reflecting the lower wages and income of those in lower economic status category.

If one or both spouses had curtailed their economic activity, respondents were asked if this had created financial hardship for their household. Overall just under a fifth (19%) said it caused little or no hardship while the remainder are more or less divided evenly between those who felt it caused some hardship and those who thought it created a lot. Cases in which a parent was a main personal caregiver were, if anything, less likely to say the curtailment of economic activity created hardship. Being of lower economic status, however, clearly increased the extent to which reduced economic activity caused a financial strain on the household.

Again, the open-ended interviews were quite consistent with the quantitative analysis. They made clear that parental caregiving was typically very demanding of time, particularly during the final stages of illness, when the child's health had severely deteriorated. Demands on the caregiver's time and effort could be overwhelming even if the period requiring such intensive care was not prolonged. Most of the parents interviewed were working before the child became ill. Their caregiving role often conflicted with their economic activities..

We had to stay home all day. We couldn't leave because he would get hungry and sometime hallucinate. He said who's coming. Why are they all coming? He was so sick... We had to stay with him all the time... I couldn't work or do anything. I worried about him all the time. When I did something else, I was still thinking of him. I had to come back to see him quickly...
[80 year old father, Rayong, Middle income]

Many parents needed to make adjustments in their working life to accommodate the demands of caregiving. The type of adjustment depended on a number of considerations including the economic status of the family, the type of work, and who else in the household was contributing to income and caregiving. One common solution was for the main caregiver simply to stop working during the period when

¹³ A mother was 3.1 times more likely to be a main personal care giver than a father in the overall sample and 2.8 times more likely among the subset of cases in which both parents were alive at the time of the deceased adult child's illness. The key informant study shows very similar results (Knodel and Saengtienchai 2002).

intensive caregiving was required and spend full time with the ill child. This was made easier if someone else could take over the work or if others in the household were still earning income.

It's a mother's responsibility. I am a mother. I couldn't do anything else at that time. I didn't work at all. I had to watch him for a full two months. However, his brothers and sisters still worked, but I was watching my son.

[61 year old mother, Phetchaburi, Poor]

Even if (the family business) was very busy, I didn't work at all. I left all the work to my daughter. I chose my son first... I let my daughter run the business.

[51 year old mother, Phetchaburi, Well off]

Reducing or stopping work is more difficult in cases where the parent is a regular employee in the formal sector than when the parent is self-employed, worked as part of a family business, or worked as a day laborer who was hired out on a job by job basis. In none of the three cases where a parent had regular outside employment, even when they were also the main caregiver, did they quit their job or completely stop their work. Rather they attempted to work around it.

Mother: My husband had to go to work (as a school janitor).

Father: But my wife had to stop selling for several months. She had to stop because our son wouldn't eat until his mother got home. He had to wait until his mother got home. So, my wife stopped working.

[54 year old Mother and 59 year old father, Phetchaburi, Middle income]

Interviewer: Did you have to stop your work (as a civil servant)?

Mother: No, I came back at lunch. Some days, I couldn't come back. I would call him first. I told him to take care of himself. I would put ice and juices in a place that he could reach.

[51 year old mother, Bangkok, Middle income]

Some parents who were quite poor simply could not afford to stop working, even though they took on the main responsibility for caregiving. Instead they also had to work around the situation. One solution was to enlist the assistance of someone else during the periods when it was necessary to work. Even if the parents were not particularly poor, some types of work such as agricultural pursuits might require tasks that, if no one else was available, left no choice but to carry on with them.

After I gave him something to eat, I would go out to earn some income. (I would stop by) to see if he already took the medicines or ate anything. After I stopped by to see him, I would see him again in the evening after I finished selling.

[45 year old mother-in-law, Chiang Mai, Poor]

Father: We took turns. One of us had to stay (at home).

Mother: At that time, (my husband) didn't stop working. He took turns with me because we still had to take care of the orchard and to spray weed-killers.

[70 year old mother and 80 year old father, Rayong, Middle income]

Funeral Expenses

Funerals usually are major social events in Thailand. They typically last at least several days and involve treating guests to refreshments or meals. In addition, the expenses occur all at once unlike costs of care and treatment that may be spread out over the period of illness. 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 as a form of insurance. In return for making regular payments, a member receives a lump sum benefit when a death in the family

occurs. In exceptional cases, funeral costs can be more than 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. As table 4 shows, 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 reflected in the fact others were also available to provide main care. Poorer parents were somewhat less likely than better off parents to have a net cost, particularly a substantial one.

[Table 4 about here]

Overall, parents were somewhat less likely to incur net funeral costs than care and treatment costs but about equally likely to incur each if only substantial expenditures are considered. Based on mean values, the net cost to parents of the funeral was approximately half as much as the costs incurred in connection with care and treatment. However the median amount spent among parents overall is actually higher, reflecting less skewed distributions of funeral costs compared to care and treatment costs. The funeral costs incurred by parents was someone greater in cases in which a parent was a main caregiver than in situations in which a parent did not assume this role. Again a clear relationship between parents economic status and the net amount paid for the funeral is apparent whether or not we limit consideration to parents who paid at least some net amount for the funeral. As with care and treatment costs, the amount spent funerals is in part a function of the ability to pay.

The open-ended interviews make clear that the net cost of the funeral was often far less than the gross cost. In a number of cases most expenses were covered by locally organized funeral insurance societies to which the family or person who died had been regularly contributing to as a member. Donations made by those attending the funeral could also be important. Contributions also occasionally came from charities. In a few cases, the total collected from various sources actually was greater than the cost of the funeral. But in others, the parents ended up in debt.

Interviewer: Did you have to spend a lot of money for his funeral?

Mother: I joined a village funeral society. I got about 15,000 Baht. Some people helped me.

They gave me 100 or 200 Baht which was a relief. I didn't have to be in debt.

[60 year old mother, Rayong, Poor]

Interviewer: When he died, did anyone help you at his funeral at all?

Mother: Yes. Some people gave us a thousand Baht. Some villagers helped out with the ceremony but I also had to borrow money from the agricultural cooperative bank to organize the funeral. I spent all the loan and the money given by the villagers in merit making (activities and donations to support Buddhism)... At night, I provided good food for the guests... I also gave money to the monks. I paid a lot... But Por Tek Tueng (a charity) helped with the coffin.

[59 year old mother, Rayong, Poor]

Means of meeting expenses.

Given the substantial amount of costs involved with care, treatment and funerals, not all AIDS parents can cover these expenses from cash in hand or their savings. Table 5 addresses some of the ways in which parents raised money to cover costs based on the direct interview survey. Results are presented both according to whether or not a parent was a main contributor to expenses and their economic status. In a small proportion of cases (14%), a parent took on extra work in order to pay for care or funeral expenses. This result agrees reasonably well with results from the key informant study which indicated that parents took on extra work in 13 percent of the cases of adult children who died of AIDS and who had a living parent (results not shown, see (Knodel, Saengtienchai, Im-em, and VanLandingham 2001)) Taking on

extra work was more common in cases where a parent was a main contributor to the expenses and inversely related to economic status. Among those who did take on work, approximately two-thirds were still engaged in this extra work. In cases of married couples, fathers were more likely to take on extra work than mothers although in a substantial share of the married couples in which extra work was taken on both parents were involved. This pattern was similar whether or not a parent was a main contributor to expenses and varied little with economic status.

[Table 5 about here]

A more common means of meeting expenses than taking on additional work was borrowing money. In almost two-fifths (39%) of the cases a parent borrowed money for this purpose. In cases in which a parent was a main contributor to the expenses, borrowing money was twice as likely as in cases where the parent was not a main contributor. Economic status is inversely related to the portion who went into debt. Among parents who did borrow money, the amount borrowed was substantial. Those who borrowed had above average expenses and the amount borrowed was just over two-fifths of their combined care, treatment and funeral expenses (results not shown in table). The amount borrowed was greater when parents were main contributors to care and treatment expenses than when they were not. Although poorer parents were more likely to borrow, they borrowed substantially lesser amounts on average than economically better off parents who borrowed.

Only about a third of cases who borrowed to meet expenses had not yet fully paid the debt off by the time of the survey. It was far more common for those who were main contributors to expenses not to have paid off the loan than for those who were not main contributors. Economic status shows no consistent association with the percent who were still in debt at the time of the survey.

Another way in which parents could meet was to sell possessions or property. In about a fifth of the cases, parents reported that they sold property or possessions to pay for the care or funeral expenses. This was more likely to occur when a parent was a main caregiver. Also the percentages who did so are inversely associated with economic status. Poorer parents were most likely to sell something to meet expenses while better off parents were least likely to do so.

The amount of money received for the property or possessions that were sold was substantial. Those who sold property or possessions, however, also had combined care and funeral expenses that were almost twice that of those who did not. Even so, the amounts received (as measured by the mean) exceeded the total costs (results not shown in table). Parents who were main contributors to expenses sold property and possessions of greater value than those who were not. Based on either means or medians, the amounts received were lowest for parents who were poor. Median values also indicate parents of better off economic status received more than those of average economic circumstances although the means show little difference between these two groups of parents.

The burden of meeting expenses associated with the illness and death of an adult child with AIDS does not necessarily fall only on the parents, even when parents are main contributors. Table 6 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 6 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).

Formal channels of assistance. As noted in the discussion of the Thai setting above, there are several important formal channels through which assistance with the expenses associated with AIDS are available in Thailand, including government health insurance, social welfare, and NGO programs. Table 7 address the extent to which health insurance and welfare or NGO assistance was received by adult children with AIDS or their families based on the direct interview survey. Results are shown both in relation to whether a parent was a main contributor to expenses and to economic status of the parents.

[Table 7 about here]

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. This was slightly more common when a parent was a main contributor to expenses than when a parent was not. Also health insurance was somewhat less likely to cover any medical costs when the parents were better off than if they were of average or poor economic status. The vast majority of cases in which insurance helped pay medical expenses involved some government program. Almost none of the cases had private health insurance. By far the most common was the 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 a welfare card directed towards those with particularly limited resources of their own. 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 a welfare card 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 benefits.

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. In contrast, more than half (56%) of those who received some coverage through insurance indicated that it helped a great deal and over a third said it helped at least some. The percent who indicated the insurance helped a great deal is inversely related to the economic status of the parents although even among the better off parents, the insurance was reported to have substantially helped in almost half of the cases.

A considerably smaller share of cases received some sort of AIDS welfare assistance (including help from NGOs). Given the nature of the programs, these payments typically were made to the person who was ill with AIDS and not directly to the parents. Nevertheless, the parents as a common contributor to expenses presumably benefited from such payments in many such cases. Receipt of assistance was substantially higher among cases in which the parents were poor than among others. It was also somewhat higher for cases in which a parent was a main contributor to care and treatment expenses.

In general the period during which welfare was provided was often rather short. In over two-fifths of the cases, payments were received only during a period of one 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 still received some welfare payment. Cases in which parents were poor also seem to receive welfare longer than others.

The amount received as welfare assistance are relatively modest compared to typical total expenses involved in care, treatment and funerals. 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, in cases in which welfare was received, close to half (46%) of the respondents reported that it was of little help and less than a fifth (19%) said that the welfare payments helped very much. The percentage reporting that welfare assistance was very helpful, however, was higher for those in which parent was a main contributor to expenses and is inversely related to the economic status of the parents.

The burden of expenses

The amount paid for care and treatment as well as for funeral costs are substantial when compared to prevailing per capita incomes. For example in 1996, the average annual per capita income in Thailand was about 76 thousand Baht. In the provinces in which we conducted our survey the equivalent figures were 30 thousand Baht in Phichit, 54 thousand in Chiang Mai, and 223 thousand in Rayong (United Nations Development Programme (UNDP) 1999). The combined costs paid for care and treatment and for the funeral in our samples averaged 37 thousand Baht both in Phichit and Chiang Mai and 97 thousand Baht in Rayong among cases in which the parents incurred any direct costs themselves (results not shown).

In order to assess in the direct interview survey the financial impact on AIDS parents of the expenses associated with care and funerals, we asked how serious a burden those combined expenses were for them. The results are shown in table 8. Approximately a third of all respondents indicated that the care and funeral expenses were a serious burden. If we limit consideration to those who paid at least something for care and funeral expenses, the figure rises 38 percent. For cases in which a parent was a main contributor to care and treatment expenses, over two-fifths (42%) or respondents said those expenses were a serious burden. Finally in cases in which a parents was both a main contributor to care and treatment expenses and had net funeral expenses, the portion who felt the expenses were serious burden approaches a half (46%).

[Table 8 about here]

There is a clear association between cases in which a parent was a main personal caregiver and a greater likelihood of reporting that the care and funeral expenses were a serious burden. A consistent and even more pronounced relationship is associated with the economic status of the respondent. Clearly poorer parents suffered more as a result the expenses involved in having an adult child die from AIDS. Over two-fifths (43%) of poor parents reported the care and funeral expenses as a serious burden. This reaches over four-fifths of the cases in which a parent of poor economic status was a main contributor and had net funeral costs.

The key informant study did not ask directly if expenses incurred by parents were a burden to them. Key informants were asked, however, if the parents economic situation had changed as a result of their adult child's illness. The results are included in table 8.¹⁴ Overall, in a fifth of the cases, the parents' economic situation was judged to have noticeably worsened. This was considerably more likely to be so if a parent was a main caregiver than the contrary. Also there is an a clear inverse association between the parent's economic status and the percent whose economic situation worsened.

Both spending and adverse economic impact are related to economic status in the direct interview survey but in opposite directions. Figure 2 compares AIDS parents in the three economic status groups in terms of their mean combined care and net funeral costs and the percent who reported that these costs were a serious burden based on the direct interview survey. Lower economic status is associated with lesser amounts spent as a result of the illness and death of the adult child but with higher percents who reported that the costs were a serious burden. Apparently, even if expenses were not large in absolute amounts for poor parents, they were still more likely be severely taxing relative to their resources. A similar pattern is evident from the key informant study results. According to the informants reports, the percentage of cases

¹⁴ Socio-economic status of the parents in the key informant study is based on the judgement of the key informant.

for which care and treatment expenses were substantial (although not explicitly for parents) was inversely related to the parent's economic status prior to the adult child's illness (results not shown, see (Knodel et al. 2001)).

[Figure 2 about here]

The open-ended interviews revealed considerable diversity in the extent to which the expenses associated with caregiving, health care, and the funeral created financial strain on the parents. In several cases the strain appeared quite considerable. Not only were the parents quite poor to begin with so that even modest absolute expenses were a burden, but in a couple of cases there also were at least two persons with AIDS involved.

It was such a mess. I didn't know what to do. I borrowed from this house or that house... Sometimes when I borrowed, they didn't charge interest. They pitied me. I had to dig potatoes to give back their money. There were a lot of expenses. I don't know how much each month. Each day I had to find them something to eat. I had to be prepared because they (the two sick adult children) had to eat when they were hungry.
[60 year old mother, Rayong, Poor]

In only a few cases, at least one parent had to increase the time spent working. This occurred in several of the cases whose economic status was quite poor. The extra work was done to meet the additional financial demands created by caregiving or the loss of income that the ill child would have otherwise been contributing to the household.

I had to do more hired work (when he was sick) because my son was the breadwinner before he got ill.
[60 year old mother, Chiang Mai, Poor]

At that time, my husband was the only breadwinner. I had to take care of my son and my grandchildren. My husband had to work harder. He worked more jobs. Besides driving a three-wheeled taxi, he did construction work. He did everything other people hired him to.
[67 year old mother, Chiang Mai, Poor]

In most cases, however, the financial strain on parents appeared not to be severe and in several, the strain seems to have been minimal. Some families were sufficiently well off that they could afford the expenses or had non-critical assets they could sell to cover the extra costs. For others, sources of relief existed that moderated the amount that the parents had to pay themselves. Families pooled resources, took advantage of various formal mechanisms that could help, and in most cases adjusted to some extent what they spent to their circumstances. In addition some of the adult children with AIDS had income or savings of their own that help cover treatment costs and other expenses. Borrowing to help meet the health care and funeral expenses was also fairly common but most parents reported they were able to clear the debt later.

We never had debts before. We did when my son got sick. After he died, we gave back all the money. Our debtors said we didn't have to hurry.
[67 year old mother, Chiang Mai, Poor]

We didn't have to sell anything but we used up our savings. We are not in trouble but we paid a lot of money.
[54 year old Mother and 59 year old father, Phetchaburi, Middle income]

Interviewer: Did you think that the expenses were a burden to your family?

Mother: Yes, because there's nothing that we could do but pay. However, his older sisters helped him a lot, too. They chipped in money because they wanted their brother to survive.
[61 year old mother, Phetchaburi, Poor]

In five of the 20 cases with whom we conducted open-ended interviews, the parents needed to sell valuables to cover the expenses associated with their child's illness and death but usually productive assets on which their income depended were not involved. Most commonly they sold gold jewelry. In only one case did the parents sell some of their land. Since for many Thais gold has traditionally served as a form of savings that could be drawn on when needed, the sales of gold may have cut into their savings. However, given that the gold was not playing any crucial part in their current support and was likely intended for situations such as they faced when their child became ill, its sale would at most have detracted from their sense of future security rather than impacting their current economic well being.

I can tell you with no shame that I sold all the jewelry I had. I thought it didn't matter. Whatever had to happen would happen anyway. One day I would have them back.
[51 year old mother, Bangkok, Middle income].

Many of the poorer parents had few assets of value that they could sell. However another avenue which could lead them to a situation of more lasting economic hardship would be to take on serious debt as a result of borrowing to cover the expenses of treatment, caregiving or the funeral. In at least one case, this appeared to have happened.

Interviewer: Did you have to borrow money from someone to cover the expenses due to his illness?

Mother: I got a loan from the Cooperative. Now, I'm still in debt. I have very little income but have to pay the interest. This is my worry.
[59 year old mother, Rayong, Poor]

Multiple deaths could also compound the impact even if the family had some savings before. In one unusual case where two sons and their wives died of AIDS and a third son was murdered, the economic impact was substantial. Even though the family had earlier sold land for a very substantial amount, the mother was eventually reduced to poverty by the series of misfortunes.

Longer Term Economic Impacts

Parents who contribute to the costs of caregiving, treatment and funerals may experience financial strain during the period of illness and shortly after the death of their son or daughter with AIDS. In cases where these expenses lead to serious depletion of savings, debt, or sale of property or possessions, longer term repercussions could also result. For those who spent within their means, however, when these expenses end, any economic hardship associated with them would also dissipate. In contrast, AIDS parents who take responsibility for expenses associated with surviving dependents of their deceased son or daughter typically continue to incur costs well beyond the death. In addition, longer term economic consequences for parents could result from the loss of any current support that the deceased adult child had been providing or from loss of future anticipated support that the child might have provided in later years of life. We asked a series of questions in the direct interview survey to directly assess assistance with expenses for dependents and loss of filial support. In addition, comparisons of information collected for both AIDS and non-AIDS parents provides an additional basis for inferring some of these longer terms consequences.

Costs for dependents. The primary involvement of AIDS parents with dependents is in association with grandchildren orphaned by the death of their adult son or daughter. Occasionally AIDS parents might also assist the spouse of the deceased child. According to our survey, as table 9 shows, in almost a third of the cases AIDS parents had assisted a dependent of their deceased child. As noted earlier, a substantial proportion of the adult children who died either were never married or had no children. In over half of the cases in which the deceased son or daughter had children of their own, a parent helped pay expenses for dependents (presumably involving expenses mainly for the grandchildren). Even when the deceased son or daughter had only a surviving spouse and no children, the parent helped support the surviving spouse

at some point in almost a third of the time. In many cases this help was probably limited to the period of caregiving when the spouse and ill son or daughter were living with the respondent.¹⁵

[Table 9 about here]

The most common source of expenses for AIDS parents in connection with dependents of the deceased child was food. In cases where no grandchildren were involved, it was relatively uncommon for the AIDS parents to incur other types of expenses (presumably for the spouse). When grandchildren were involved, expenses for a whole array of items were relatively common. In about a third of such cases, the AIDS parents indicate they paid for school expenses. Some of these children were below school age, however, so it is quite possible that expenses for school in the future will be covered by some AIDS parents who have yet to do so. More broadly, as noted above, some AIDS parents are also likely eventually to inherit responsibility for grandchildren who are currently being cared by their deceased children's surviving spouses since some of the latter are HIV infected and are likely to die before the grandchildren grow up. This will also result in future expenses to the AIDS parents that are not yet evident at the time of our survey.

Loss of filial support. From a longer term perspective, the potentially most serious economic impact for some AIDS parents is the loss of the current and future support that the deceased would have provided. If the deceased son or daughter had been contributing to the parents' household income, especially when the adult child was a main contributor, the loss of income could lead to a sustained long term reduction in economic well-being. As table 10 shows, in over 70 percent of the parental households covered by our survey, the deceased child provided some material assistance to the parents during the year prior to becoming seriously ill and in almost a third had been the main income provider. These overall proportions are likely inflated somewhat by the skewed nature of our sample as discussed above. Particularly noteworthy is the strong inverse association between the parents' economic status and the loss of a child who was a main income provider. Deceased children of poorer parents were more than twice as likely to have been the main income earner than those of better off parents, most likely reflecting a greater need for such support among poor older persons.

[Table 10 about here]

The amount of income provided by the deceased child during the year prior to being ill among those who contributed income to the parental household was fairly substantial in relation to average per capita income in Thailand. This is particularly true among deceased children who were main providers for the household. The contributions to better off economic status parents were greater in absolute amounts than to those of lower economic status based on the mean amount provided. However, among cases where the deceased child was a main provider, there is little relationship between the economic status of the parents and median amount of monetary support received.

Adult children can also provide important services to their older age parents, particularly if they coreside with them. As table 10 indicates, regardless of economic status, over half of the deceased children were coresident with the parent prior to serious illness and an additional share lived with the parents at least part of the year or intermittently spent time living in the parental home. These proportions are quite high reflecting the skewed nature of our sample. In most cases where the deceased adult children had been coresident, they had provided some help with household chores or with family economic activities and

¹⁵ This is suggested by responses to a question asking parents who had contributed support if they expected to continue such support. In most cases in which the deceased adult child had a spouse but no children, the respondents said they did not expect to be continuing covering expenses. In contrast, if the deceased son or daughter had child, a majority said they expected to continue support (results not shown in table).

almost half (48%) had provided regular assistance. The extent of regular assistance is particularly high among parents who were poor.

In order to assess if living arrangements were adjusted to make up for the loss of a coresident adult child, we asked respondents if someone else moved into the household following the illness and death of their adult child with AIDS to assist with support and maintenance of the household. Only a minority of respondents reported anyone moved in. Even when conditioned on those parental households in which the deceased child was continuously coresident before the illness, only eight percent of respondents reported someone else augmenting the household. There appears to be little relationship between economic status and someone else moving in response to the loss of the child who died with AIDS.

We directly asked AIDS parents to assess the extent to which the loss of income or services provided by the deceased child created difficulties for their financial situation. Over half of the respondents reported that the situation was either much more or somewhat more difficult. The proportion reporting that the situation was much more difficult shows a pronounced inverse association with their economic status. Only a small minority (8%) of economically better off respondents reported that the loss of the income or services provided by the deceased child created serious difficulty compared to 44 percent of those who were poor.

The open-ended interviews also made clear that the loss of the support that the adult child who died had been providing to the parents could have serious and lasting economic consequences for parents in certain cases. This usually occurred because the child was coresident and had been the main breadwinner for the household or played a crucial role in their ability to make a livelihood.

While he was alive, his father would schedule shows for him and he would go to play *likae* (local type of theater). Now that he's gone, we don't take any jobs because we don't know who can be the actor... *Likae* was our job. Without him, there's no job.
[61 year old mother, Phetchaburi, Middle income]

At that time, I still had some money and savings. He gave some money to me. He earned good income. He went out on fishing trips and gave me 3-5,000 Baht a month. I could save up some of the money. Now, I don't have any savings.
[65 year old mother, Rayong, Poor]

Lasting hardship could also arise because the child had been making regular contributions or remittances to the parents. Although a number of the deceased adult children gave monetary gifts to their parents at least occasionally, in only one such case did it seem that the loss of these contributions were crucial for the longer run economic security of the parents. More commonly the contributions had mostly token significance. In most cases the child with AIDS was not playing a crucial role in the economic support of the parents.

(Now) if I don't have money, I have to borrow from other people. Before, I still got some money from my son. Perhaps 300 Baht every 15 days. I could still hope to get some money. Now, I don't know who to depend on.
[65 year old father, Bangkok, Poor]

Interviewer: Now that he's gone, have you lost some of your income because he gave you some money when he was alive?

Parent: Sometimes but that doesn't cause us any troubles because we still can help ourselves.
[54 year old mother and 59 year old father, Phetchaburi, Well off]

To a large extent the impressions gained from our open-ended interviews are consistent with our quantitative analysis. Neither our qualitative nor quantitative data, however, are able to accurately anticipate what the eventual effect will be on the parents when they reach old age and may need to depend

on adult children for their support. In two cases in our limited sample of open-ended interviews, the parents had no remaining living children after the child with AIDS died. However in both of cases the parents had or were entitled to retirement benefits and appeared to have sufficient financial resources to ensure their future economic security. In the remaining cases, the parents had other living adult children who presumably will fulfill their expected role to provide old age assistance if needed.

Comparisons with non-AIDS parents. As mentioned in the description of the direct interview survey design, most of the deaths of the adult children from AIDS occurred between six months and three years prior to the survey. Thus comparisons between AIDS parents and those who had not experienced any recent adult child death with respect to their economic circumstances, and particularly changes in those circumstances over the prior three years, should reflect any sustained intermediate-term economic impact of the loss of a child to AIDS. Table 11 presents the relevant comparisons.

[Table 11 about here]

AIDS parents were more likely than the comparison group to judge their current financial status as difficult and less likely to indicate it as comfortable. This could reflect pre-existing differences between two groups given that the AIDS parents appear to be from somewhat more disadvantaged backgrounds.¹⁶ However, AIDS parents were also more likely to indicate that their financial status had become much worse over the past three years thus providing more convincing evidence that the loss of an adult child to AIDS had a detrimental effect on their economic situation. Nevertheless, when AIDS parents were asked an open-ended question as to why their financial status worsened, less than a third specifically mentioned the costs of the child's illness as the main reason. Note that the period covered coincided with the economic downturn in Thailand associated with the Asian economic crisis of recent years. This may account for why substantial proportions of non-AIDS parents also reported that their financial status worsened.

AIDS parents were also more likely than non-AIDS parents to indicate that they were currently experiencing debt, that their current debt was serious, that they were in debt three years prior to the interview, and that the debt at that time was serious. In response to an open-ended question, approximately a fifth of the AIDS parents who said their debt was serious indicated that their child's illness the reason for their debt, both with respect to the current debt and the earlier debt.

As noted in the section on the Thai setting, many older-age parents depend on adult children for at least some of their economic support and that this familial system of support for older parents is closely linked to coresidence with or living nearby an adult child. Table 12 presents comparisons between AIDS and non-AIDS parents with respect to living arrangements, several aspects of household composition, and support from household members and adult children in general.

[Table 12 about here]

AIDS parents were somewhat less likely than non-AIDS parents to be coresident with an adult child at the time of the survey. Nevertheless, an adult child was present in approximately two-thirds of the AIDS parents households. In contrast, AIDS parents households were somewhat more likely to contain a minor aged member and distinctly more likely to contain a foster child (i.e. whose parents are not present even if

¹⁶ The AIDS parent respondents are somewhat less educated than the non-AIDS parents. Overall the AIDS parents' households are also less wealthy judging from household possessions. In addition, based on our measure of economic status, AIDS parents households are somewhat more skewed towards poorer households than those of non-AIDS parents. Although the less favorable economic indicators for AIDS parents could reflect the impact of losing a child to AIDS, the educational attainment distribution is independent of any such effect but would usually be correlated to economic status. Thus it seems likely that overall the non-AIDS parents comparison group were probably better off than the AIDS parents even before the latter experienced the illness and death of their adult child.

alive) or a double-orphaned child (i.e. whose both parents are deceased). Although there is little difference between AIDS and non-AIDS parents with respect to having a child live nearby or in the same locality, AIDS parents are somewhat more likely to have the nearest child live at some distance. Rarely, however, did the death of their son or daughter leave AIDS parents with no living children.

The average number of household members who were employed during the prior year and who contributed to the support of the household is only slightly less for households of AIDS parents than those of non-AIDS parents. A more pronounced difference is evident with respect to support from children in general (including those living outside the household). AIDS parents were less likely than non-AIDS parents to have received significant cash (defined as 1000 Baht or more) from an adult child during the previous year or to have received material gifts worth an equivalent amount. At the same time, AIDS parents were also less likely themselves to have provided significant cash or material gifts to their children. A substantially higher proportion of AIDS parents indicated that they received less support from their children now than three years ago and that half of the AIDS parents whose support was reduced stated the reason was the death of their child.

Conclusions

The collection of systematic empirical data on the impact of the AIDS epidemic on older persons through the illness and death of an adult son or daughter poses serious challenges. Such data, however, are critical for making a realistic assessment of the problems and needs of older persons in their role as AIDS parents. While reliance on anecdotal evidence or cases studies can be suggestive of the situation and help identify relevant issues, they cannot ultimately substitute for broad based and systematic evidence of their dimensions and prevalence such as we attempt to provide for Thailand based on a multi-method approach.

Overall, the loss of a child to AIDS has a serious economic impact only for a minority of AIDS parents. Taken together, our three data sources provide a reasonably consistent picture that helps explain why this is so. Those parents who spent substantial amounts on treatment tended to be economically better off than average and hence could likely afford to do so without lasting financial hardship. For many others, health care costs were largely covered through government insurance or welfare assistance. Funeral expenses, while high, were often substantially defrayed by the fact the family belonged to a local funeral society to which they regularly contributed and which paid much of cost and by customary contributions by community members attending the funeral. Families sometimes pooled resources, took advantage of various formal mechanisms that could help, and parents in most cases adjusted what they spent to their circumstances.

At the same time, the poor appear to be the most adversely affected. Even though they spent less on treatment, caregiving, and funeral expenses, the amounts were more devastating for them relative to their economic resources. Expenses that were not covered, such as transportation to health care sites and the costs of some medicines, even if they were subsidized, could create financial hardship for those with no savings and few if any assets and lead them into debt. Also disruption of normal economic activities could contribute to the burden particularly of the poor. One implication of this finding is that interventions intended to help older-aged parents deal with the financial strains associated with losing an adult child to AIDS should take into account the considerable range of vulnerability that exists and target those who are particularly susceptible to resulting economic hardship.

The one issue relating to older persons that has received some attention in the context of the HIV/AIDS epidemic is the role of grandparents in caring for AIDS orphans. Our research in Thailand indicates that only a minority of the AIDS parents fostered grandchildren left behind by their deceased son or daughter. Interestingly, a systematic quantitative study in Zaire, found that only about a third of AIDS orphans were being cared for by their grandparents (Ryder, Kamenga, Nkusu, Batter, and Heyward 1994) cited in (Kinsella and Velkoff). One important reason for this was that for over half of the AIDS parents, the deceased son or daughter had no children. Another is that each set of orphaned grandchildren are likely to have two sets of living grandparents, only one of which at most would take custody of them. In

circumstances where grandchildren did exist, however, it was fairly common for grandparents to be involved in raising them.

Some potential impacts of losing an adult son or daughter to AIDS may not become apparent until long after the adult child's death. In particular, the full implications of the loss of a potential provider of care in old age or a contributor to material support may not become evident until the parents' health and physical stamina decline resulting in frailty and a need to depend on others for material support. Our study is likely to miss these potential long term effects because insufficient time had past at the time of data collection for them to manifest themselves. At the same time, most AIDS parents have other surviving children on whom they can depend, reflecting the high fertility levels that prevailed in Thailand until several decades ago. Thus for many the loss of just one son or daughter may not seriously jeopardize their old age care and support from adult children.

The particular culture, politics, and levels of socio-economic development of any setting as well as the dimensions and characteristics of the epidemic are likely to condition the nature and magnitude of its impact on older persons. Thailand shares important characteristics with many of countries with moderate to severe levels of the HIV/AIDS epidemic that are likely to condition the implications for parents and families. These include the heterosexual nature of most transmission and the dependence of parents on adult children for old age support. There are also features of the Thai situation, however, that distinguish it from many other developing countries, particularly those in Africa where the severity of the epidemic is far worse. Many of these features are likely to moderate the impact of the epidemic on older-aged Thai parents compared to parents in other settings where they are absent. These include a well developed public health system, reasonably widespread availability of government health insurance, an unusually successful effort to openly confront the epidemic and to educate the public about it, and low fertility among the generation of adults in the prime AIDS ages combined with high past fertility of their parents. Moreover, Thailand has its own particular cultural setting, strongly influenced by its heritage of Theravada Buddhism, within which the causes and consequences of epidemic play out. Thus while the findings of our study are likely to have relevance in some respects for other developing countries with AIDS epidemics, they also need to be understood in terms specific to the Thai context.

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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 (deceased adults for whom information was reported)		Direct interview survey with AIDS parents	Open-ended interviews with AIDS parents
		All	Cases with supplemental information		
Total	--	768	258	394	20
Chiang Mai	6.48	137	40	153	6
Rayong	4.23	177	20	137	8
Phichit	1.51	68	28	104	
Chiang Rai	7.60	138	42		
Khon Kaen	1.14	42	30		
Phetchaburi	3.30	87	39		3
Phuket	3.78	48	28		
Ubon Ratchatani	1.15	49	23		
Bangkok	1.90	22	8		3

Note: The key informant study also collected information on currently symptomatic cases but are excluded in the present analysis and not included in the numbers shown. One case with supplemental information did not die locally and is not included in the 768 cases on which basic tabulations are based.

Table 2. Involvement of parents in expenses related to care and treatment of adult children who died of AIDS, by caregiving and economic status

	All cases	Was parent a main personal caregiver?		Economic status		
		No	Yes	Better off	Average	Poorer
N of cases	394	113	281	75	131	187
% 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
Amount parents paid for care and treatment (in Baht)						
<i>All cases</i>						
Mean	33871	28569	35890	70590	32977	19437
Median	7500	3000	10000	20000	15000	3000
<i>Parent was a main contributor to expenses</i>						
Mean	48119	62767	44845	90205	42147	31312
Median	20000	15000	20000	30000	20000	9250

Source: Direct interview survey

Table 3. Curtailment of economic activities by parents of adult children who died of AIDS, by parents' role in caregiving and contributing to care expenses and economic status

	All cases	Was parent a main personal caregiver?		Economic status		
		No	Yes	Better off	Average	Poorer
N of cases	394	113	281	75	131	187
% of cases in which a parent curtailed economic activity	47.0	23.9	56.2	41.3	46.6	49.2
Among married couples, percent in which:						
only father curtailed economic activity	7.1	3.6	8.0	7.1	8.8	5.6
only mother curtailed economic activity	17.3	12.5	18.6	12.5	16.5	20.6
both parents curtailed economic activity	24.3	8.9	28.6	23.2	22.0	26.2
Duration of work curtailment among those who curtailed economic activity (a)						
mean duration (in months)	3.1	2.3	3.2	3.4	3.2	2.9
median duration (in months)	1.0	1.0	1.0	1.0	2.0	1.0
% stopping 3 months or more	32.6	19.2	34.8	29.0	44.1	26.7
Among those who curtailed economic activity:						
<i>Amount of forgone income (b)</i>						
mean (in Baht)	8604	4332	9370	11318	8836	7595
median (in Baht)	2500	2500	2800	6750	2500	2500
% forgoing 5000+ Baht	41.4	22.2	44.9	60.7	38.6	36.4
<i>Extent to which curtailment of economic activity created a financial hardship (% distribution)</i>						
a lot	35.5	38.5	35.0	22.6	26.2	45.6
some	36.1	42.3	35.0	22.6	39.3	38.9
a little or not at all	28.4	19.2	29.9	54.8	34.4	15.6
total percent	100	100	100	100	100	100

Source: direct interview survey.

Notes: (a) In cases where both parents curtailed their economic activity, duration refers to the longer period if the periods were unequal..

(b) In cases where both parents curtailed their economic activity, the forgone income refers to the combined income forgone by both parents.

Table 4. Involvement of parents in expenses related to the funeral of adult children who died of AIDS, by caregiving and economic status

	All cases	Was parent a main personal caregiver?		Economic status		
		No	Yes	Better off	Average	Poorer
N of cases	394	113	281	75	131	187
<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
Net amount parents paid for funeral costs (in Baht)						
<i>All cases</i>						
Mean	18193	14298	19440	29154	20505	11611
Median	10000	2750	10000	16000	15000	5000
<i>Parent paid at least some</i>						
Mean	24488	22468	24790	38361	24682	17276
Median	15000	15000	16000	30000	20000	10000

Source: Direct interview survey

Table 5. Selected means by which parents raised money to pay for care and funeral expenses of adult children who died of AIDS, by parents' role in contributing to care expenses and economic status

	All cases	Was parent a main contributor to expenses?		Economic status		
		No	Yes	Better off	Average	Poorer
N of cases	394	146	244	75	131	187
Taking on extra work						
% of cases in which a parent engaged in extra work to pay for care of funeral expenses	14.2	6.2	18.9	6.7	13.0	18.2
Of those who took on extra work, % still in engaged	66.1	**	67.4	**	76.5	64.7
Among married couples, percent in which:						
only father took on extra work	8.2	5.7	9.3	5.4	6.6	11.2
only mother took on extra work	2.4	1.4	2.7	0.0	1.1	4.7
both parents took on extra work	7.8	2.9	9.3	3.6	7.7	10.3
Borrowing money for care or funeral expenses						
% of cases in which a parent borrowed money	38.6	24.0	48.0	30.7	37.4	42.8
Among parents who borrowed:						
<i>Amount borrowed (in Baht)</i>						
mean	27103	22014	28638	44391	28898	20956
median	15000	15000	15000	30000	20000	10000
<i>% still in debt</i>	32.9	20.0	36.8	34.8	26.5	36.3
Sale of property and possessions to pay for care or funeral expenses						
% of cases in which a parent sold property or possessions	20.1	10.3	26.2	16.0	20.6	21.4
<i>Amount received for sold property or possessions</i>						
mean	154721	88127	168913	264882	268550	41982
median	10000	7000	11300	24000	14000	10000

Source: Direct interview survey

Table 6. 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 7. 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	Was parent a main contributor to expenses?		Economic status		
		No	Yes	Better off	Average	Poorer
N of cases	394	144	242	75	131	187
Health insurance						
<i>% of cases in which health insurance helped paid for medical costs</i>	59.6	55.6	61.6	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	41.3	55.7	47.4	60.0	44.7
welfare card	22.0	28.8	18.1	7.9	15.0	31.6
civil service/social security system	12.9	12.5	12.8	34.2	10.0	7.9
private	0.9	1.3	0.7	0.0	1.3	0.9
other	13.8	16.3	12.8	10.5	13.8	14.9
total percent	100	100	100	100	100	100
<i>Extent to which insurance helped with expenses (% distribution)</i>						
very much	55.7	60.3	52.4	48.6	52.6	60.2
some	34.6	30.8	37.4	37.8	41.0	29.2
not much	9.6	9.0	10.2	13.5	6.4	10.6
total percent	100	100	100	100	100	100
AIDS Welfare assistance (a)						
<i>% of cases that received welfare payments</i>	18.8	15.4	20.7	14.9	14.0	23.9
Among cases who received welfare:						
<i>Duration of payments (% distribution)</i>						
1 month or less	41.2	30.0	46.8	**	44.4	33.3
2-5 months	17.6	20.0	14.9	**	5.6	21.4
6+ months	20.6	20.0	21.3	**	38.9	16.7
family still receives payments	20.6	30.0	17.0	**	11.1	28.6
total percent	100	100	100	**	100	100
<i>Amount received</i>						
mean	10342	13704	9095	3818	22416	7189
median	4000	4500	4000	4000	6000	3850
<i>Extent to which welfare helped with expenses (% distribution)</i>						
very much	19.1	11.1	22.4	9.1	13.3	23.8
some	35.3	44.4	30.6	9.1	60.0	33.3
not much	45.6	44.4	46.9	81.8	26.7	42.9
total percent	100	100	100	100	100	100

Source: Direct interview survey.

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

** = less than 10 cases.

Table 8. The burden of parental expenses related to adult children who died of AIDS and the percent of parents whose economic situation noticeably worsened, by caregiving and economic status

	All cases	Was parent a main personal caregiver?		Economic status		
		No	Yes	Better off	Average	Poorer
From direct interview survey						
<i>N of cases</i>	394	113	281	75	131	187
<i>Extent to which care and funeral expenses were a serious burden (percentages)</i>						
All cases	33.8	22.1	38.6	18.7	29.8	42.5
Parent paid at least some for care/funeral	38.2	28.4	41.5	20.0	32.2	50.6
Parent was a main contributor to care expenses	41.8	34.1	43.5	18.9	36.4	57.8
Parent was a main contributor to care expenses and had net funeral costs	45.6	43.8	45.9	23.3	43.1	62.5
From the key informant study						
<i>N of cases</i>	199	69	128	45	92	51
<i>Among cases with a living parent, percentage whose parents' economic status noticeably worsened since the time of the adult child's illness</i>	19.6	13.0	23.4	6.7	19.6	31.4

Table 9. Parental involvement in expenses related to dependents of adult children who died of AIDS

	All cases	Cases in which the adult child who died	
		had surviving spouse but no children	had children
N of cases	394	43	193
% of cases for whom a parent helped pay expenses for a dependent	31.5	30.2	57.0
% of cases for whom a parent helped pay for:			
medicine	18.8	4.7	37.3
transportation	19.8	11.6	38.0
food	31.0	30.2	56.3
clothing	23.5	4.8	46.9
school expenses	16.1	n.a.	32.8

Source: Direct interview survey.

Table 10. Contribution of adult child who died of AIDS to parental household

	All cases	Economic status		
		Better off	Average	Poorer
N of cases	394	75	131	187
Contribution of the deceased adult child to parental household income during year prior to serious illness (% distribution)				
main provider	32.4	17.3	26.0	43.2
some but not over half	15.6	17.3	13.7	16.2
only a little or other	23.2	29.3	26.0	18.9
none	28.8	36.0	34.4	21.6
total percent	100	100	100	100
Amount of income provided during year prior to serious illness				
<i>Among deceased children who contributed any income</i>	13341	20280	11323	12415
mean	6000	12000	5700	4750
median				
<i>Among deceased children who were main providers</i>	16316	22460	15058	15951
mean	10400	12000	11400	10000
median				
Coresidence and household services				
<i>% of deceased adult children who were coresident with a parent before becoming seriously ill</i>				
continuously	57.6	58.7	61.8	54.0
part of time	16.0	12.0	14.5	18.7
<i>Among coresident deceased adult children, extent of help they provided with household chores or family economic activities (% distribution)</i>				
regularly	47.9	43.4	44.0	52.2
irregularly	29.0	43.4	25.0	26.5
% of parental households in which someone moved in to help with support and maintenance since adult child with AIDS became ill and died:				
among all parental households	5.8	4.0	7.6	5.3
among parental households in which deceased child was continuously coresident before illness	7.5	4.5	8.6	7.9
Extent to which loss of income or services provided by the deceased child makes financial situation difficult (% distribution)				
much more difficult	27.4	8.2	15.0	44.0
somewhat more difficult	26.1	28.8	25.2	25.7
not at all	23.7	35.6	32.3	12.6
child did not contribute	22.9	27.4	27.6	17.7
total percent	100	100	100	100

Source: Direct interview survey.

Table 11. Financial status and indebtedness of AIDS and non-AIDS parents

	AIDS parents households	Non-AIDS parents households
Financial status		
<i>Current financial status</i> (% distribution)	12.7	20.8
Comfortable	30.2	38.4
Neither comfortable nor difficult	57.1	40.8
Difficult	100	100
Total		
<i>Change in financial status over past 3 years</i> (% distribution)		
the same or better	46.4	53.7
somewhat worse	34.0	35.9
much worse	19.5	10.4
total	100	100
<i>Among those whose financial status worsened, % who give costs of child' illness/death as a reason</i>	28.4	--
Indebtedness		
<i>% with any debt</i>	43.4	39.6
currently	44.5	37.6
3 years earlier		
<i>% with somewhat or very serious debt</i>	33.8	26.8
currently	30.5	24.0
3 years earlier		
<i>Mean debt</i> (in 1000s of Baht)	104.2	116.0
Currently	155.3	142.8
3 years earlier		
<i>% who give costs of child' illness/death as a reason among those with serious debt</i>		
currently	19.6	--
3 years earlier,	18.3	--

Source: Direct interview survey.

Table 12. Living arrangements and household composition, support from household members and support exchanges with children, AIDS and non-AIDS parents

	AIDS parents households	Non-AIDS parents households
Living arrangements and household composition		
<i>% of households with</i>	65.0	72.9
a coresident adult child		
with a minor (under 15) in household	56.6	48.7
with a foster child in household (a)	31.5	12.8
with a double-orphaned child in household (b)	11.7	0.3
<i>Location of nearest adult child (% distribution)</i>		
same house	63.7	72.1
next door/ nearby	13.2	11.4
same locality	3.0	4.5
same district	5.1	4.8
same province	5.1	2.7
elsewhere	7.4	4.5
no adult child	2.5	0.0
total	100	100
Support from household members		
Mean number of members employed last year	2.3	2.5
Mean number of members who contribute to support.	2.3	2.4
Support exchanges with children		
<i>% of respondents who received from at least one adult child during previous year:</i>	67.8	72.3
1000+ Baht in cash	61.2	69.9
material gifts worth 1000+ Baht		
<i>% of respondents who gave to at least one adult child during previous year:</i>	36.8	45.5
1000+ Baht in cash	27.9	36.2
material gifts worth 1000+ Baht		
<i>Change in support from children</i>		
% who receive less support from children now than 3 years ago	41.9	25.9
Among those receiving less support from children currently than 3 years earlier, % who give child' illness/death as a reason	47.3	--

Source: Direct interview survey.

Notes: (a) a foster child is a child under age 15 whose parents do not live in the same household.

(b) A double-orphaned child is one whose both parents are dead.

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

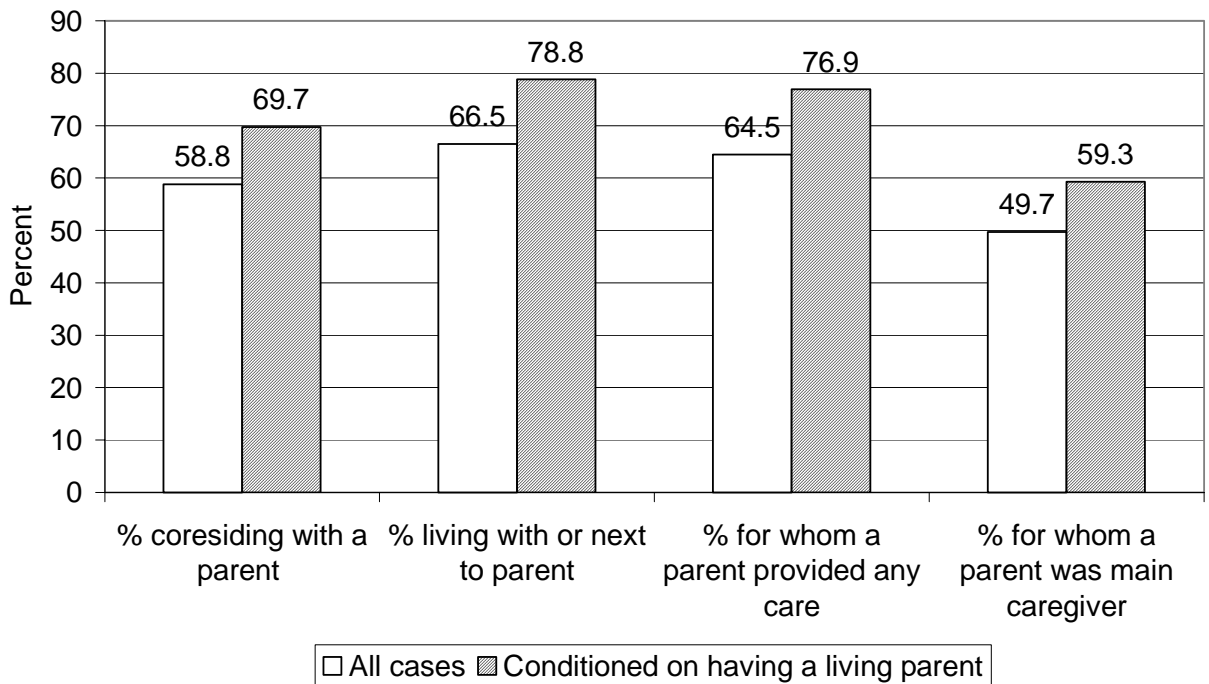


Figure 2. Mean combined care and net funeral costs to parents and percent for whom costs were a serious burden (source: AIDS parents survey)

