John Knodel and Wassana Im-em

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

PSC Research Report

Report No. 02-504

Revised October 2003

PSC POPULATION STUDIES CENTER
AT THE INSTITUTE FOR SOCIAL RESEARCH
UNIVERSITY OF MICHIGAN

The Population Studies Center (PSC) at the University of Michigan is one of the oldest population centers in the United States. Established in 1961 with a grant from the Ford Foundation, the Center has a rich history as the main workplace for an interdisciplinary community of scholars in the field of population studies. Currently the Center is supported by a Population Research Infrastructure Program Grant (R24) from the National Institute of Child Health and Human Development, and by a Demography of Aging Center Grant (P30) from the National Institute on Aging, as well as by the University of Michigan, the Fogarty International Center, the William and Flora Hewlett Foundation, and the Andrew W. Mellon Foundation.

PSC Research Reports are prepublication working papers that report on current demographic research conducted by PSC-affiliated researchers. These papers are written for timely dissemination and are often later submitted for publication in scholarly journals. The PSC Research Report Series was begun in 1981. Copyrights for all Reports are held by the authors. Readers may quote from this work as long as they properly acknowledge the authors and the Series and do not alter the original work.

PSC Publications
http://www.psc.isr.umich.edu/pubs/

Population Studies Center, University of Michigan
PO Box 1248, Ann Arbor, MI 48106-1248 USA

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

(Revised October 4, 2003)

John Knodel
Professor of Sociology
Population Studies Center
University of Michigan
PO Box 1248
Ann Arbor, MI 48106-1248
jknodel@umich.edu

Wassana Im-em
Institute for Population and Social Research
Mahidol University
Salaya, Nakorn Pathom 73170
Thailand

***Acknowledgements**: Financial support for this study was provided by the National Institutes of Aging as part of the project "Socio-demographic Impact of AIDS on Older Persons" (grant AG15983) and the Fogarty International Center (grant 2 D43 TW00657-06) "Population Research and Training in Developing Countries".). Guidance and assistance was provided throughout the research process by our co-investigators Mark VanLandingham, Chanpen Saengtienchai, and Jiraporn Kespichayawattana.

Abstract

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

We examine the economic consequences for older-age parents of losing an adult child to AIDS in Thailand based on quantitative and qualitative data derived from a key informant study, a direct interview survey with parents, and open-ended interviews. This multi-method approach generates complementary data sets allowing a comprehensive investigation of relevant issues. Our main findings are as follows. 1) AIDS parents were frequently and substantially involved in paying for their children's care and treatment costs, but government health insurance and to a less extent welfare services helped alleviate these expenses. 2) Parental caregiving often involved disruption of economic activity, although the generally short duration of caregiving lessened the extent of opportunity costs. 3) AIDS parents frequently paid for their children's funeral costs, with funeral society memberships and customary contributions from those attending substantially reducing these costs to parents. 4) Although a minority of all parents were involved in supporting AIDS orphans, orphaned grandchildren often ended-up with their grandparents. 5) Most deceased children had contributed financially to the parental household before becoming ill, but with a minority acting as main providers. Poorer parents, however, were far more likely than better off parents to lose a main provider and to experience severe financial hardship because of this loss. 6) Although poorer AIDS parents spent much less than their better off counterparts on expenses related to the illness and death of their children, they were burdened to a greater extent by these expenses. One important implication of these findings is that programs are needed that recognize and address the plight of older persons who lose a child to AIDS. These programs must take intro account the considerable range of vulnerability that exists and target those who are most susceptible to resulting economic hardship.

Key words (in title): AIDS; older persons; consequences; Thailand; parents; economic
Key words (not in title): caregiving; households; methods; funerals; impact

HIV and AIDS have had devastating effects around the globe, and particularly in nations and communities with significant epidemics. On a macro level, health services, educational systems, labor forces, commercial enterprises, and food security are all vulnerable to adverse consequences (e.g., Barnett, Whiteside and Desmond 2001; Bloom and Lyons 1993; Godwin 1997; UNAIDS 2002). In addition, at the individual level, the illness and death of those with AIDS can profoundly affect family members and significant others emotionally, economically, socially, and physically. Since most adults who die of AIDS are in their 20s, 30s, and 40s, many have living parents in their 50s, 60s, and 70s. In countries hardest hit by AIDS, these AIDS parents are not only very numerous but are particularly vulnerable to an array of adverse consequences (Knodel and VanLandingham forthcoming-a; Knodel, VanLandingham, and Watkins forthcoming). Yet empirical research on the impact of the epidemic on AIDS parents is largely lacking, as indeed is any more general recognition that the epidemic has serious consequences for the older population. The present study focuses on the economic consequences for parents of losing an adult child to AIDS in Thailand. The analysis is based on a combination of quantitative and qualitative data derived from three complimentary data collection approaches. Although other studies have empirically investigated the economic consequences of AIDS for the household in Thailand and elsewhere, none has focused specifically on the impact for older aged parents (Bloom and Godwin 1997; Pitayanon, Kongsin, and Janjareon 1997; Im-em and Phuongsaichai 1999; Kongsin et al. 2001).

Pathways of Impact

An adult child's illness and death from AIDS can adversely affect the economic well-being of parents through multiple pathways. Most commonly acknowledged among these is the responsibility they take in fostering grandchildren orphaned by AIDS (UNAIDS 1999; UNICEF 2000), although recent recognition also has been given to their critical role as caregivers for their HIV-infected adult children (United Nations 2002). Figure 1 identifies these and several other common routes of impact, and provides a conceptual framework to guide our analysis.

First, Figure 1 presents potential adverse economic impacts on AIDS parents in a timeframe. During their adult child's illness, AIDS parents may take considerable time away from economic activities to help with caregiving, and thus incur a temporary loss of income. If the parents are engaged in local commerce such as marketing produce or running a small shop, as is common in many developing countries, fear of contagion may lead to a loss of customers, especially if the ill child lives with or is cared for by the parents. And regardless of whether or not parents give care to or coreside with their ailing adult child, they may shoulder treatment and health care expenses. The combined costs for medicines, health service fees, hospitalization, and transportation to health service facilities, as well as the daily living expenses when the ill son or daughter coresides, can be substantial. Parents may deplete their savings, sell possessions or property, and go into debt to cover such expenses. At the death of the adult child, funeral costs can be considerable and lead to similar consequences. If parents take responsibility for orphaned grand children, the associated school, health care, and daily living expenses for the orphans and opportunity costs associated with child care will continue for years and may further deplete financial resources. Moreover, if the parents were dependent on their deceased son or daughter for direct material support or for contributions to the parental household's economic activities, a sustained reduction in household income could result. Finally, the loss of the adult child can have long-term implications for parental economic well-being through the loss of old-age support that the adult child would otherwise have provided.

Figure 1. Potential Pathways and Conditioning Factors through which the Illness and Death an Adult Child with Aids Can Adversely Impact the Economic Well-Being of Older-Age Parents

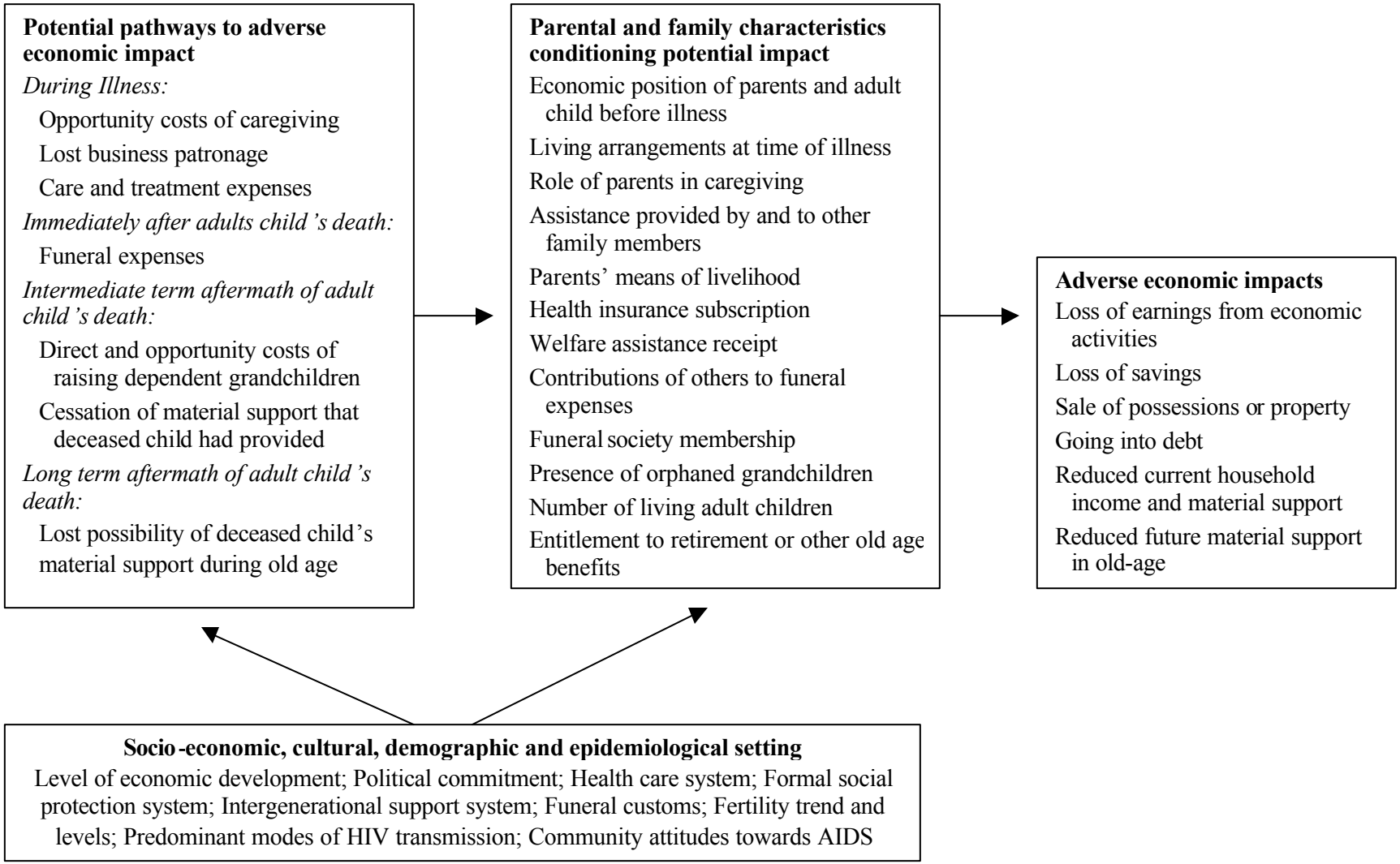


Figure 1 also indicates how economic impacts will be influenced by circumstances specific to AIDS parents and their situation. Perhaps the most important of these is the economic status of the parents and the adult child prior to the onset of illness. Clearly parents who are better off economically will be in a better position than poorer parents to withstand expenses or loss of income associated with the illness and death of their child. Likewise, adult children who are better off will be able to help defray more of the costs of care and treatment themselves. Living arrangements at the time of illness will influence the level of parental involvement in care and related expenses. Parents who coreside with the child at the time of illness or live nearby are more likely than parents who live elsewhere to give care and pay treatment expenses. They are also probably more likely to inherit responsibility for dependent orphans (Saengtienchai and Knodel 2001). The economic burden on the AIDS parents will also depend on how much other family members assist or depend on them financially. For example, siblings of the afflicted son or daughter may help pay care and treatment expense. On the other hand, the AIDS parents may have on-going obligations to support their own elderly parents or have other children of their own who still depend on them. Whether parents are vulnerable to loss of business patronage will depend on the way they earn their livelihood. Health insurance and welfare assistance provided by the government or NGOs (non-governmental organizations) can also ease the financial burden on parents. Customary contributions of community members to funeral expenses or reimbursement as a member of a funeral society can lessen the amount parents have to pay themselves. Whether the AIDS parents foster orphaned grandchild will depend on whether any exist and, if so, who else is available to provide foster care. Finally, the implications for old-age support will depend on whether the parents have other adult children available to take on this responsibility or formal sources of retirement or old-age benefits.

Figure 1 also illustrates how both the likelihood that AIDS parents will experience various pathways and the distribution of characteristics conditioning the impacts will be influenced by the socioeconomic, cultural, demographic, and epidemiological characteristics of their settings. These include level of economic development, political commitment to addressing the epidemic, the health care system, the formal social protection system, the nature of the intergenerational support system, funeral customs, past and present fertility levels, the predominant modes of HIV transmission, and community attitudes towards AIDS. The influence of some of these setting characteristics may be complex because of interactions with other characteristics. At any rate, the economic impact on AIDS parents may vary considerably from setting to setting and interpretations of empirical findings must take this into account. In the context of the present study, it is necessary to consider several aspects of the Thai setting described in the following section that are likely influence our results.

Many of the potential economic consequences shown in Figure 1 would follow from the illness and death of an adult child from any cause and thus are not all unique to AIDS. However, some aspects of AIDS – such as the types of symptoms suffered, their duration, and the nature of community reaction – may increase the potential severity of economic consequences. In addition, the likelihood that dependent children of persons with AIDS will need foster care is high since the initially infected parent can transmit HIV to the other. Most significantly, however, in countries with substantial epidemics, AIDS can be the most likely cause that older persons lose their adult children. In Thailand, for example, where adult AIDS 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 up to 70 percent (Wachter, Knodel, and VanLandingham 2002). In settings, such as in Africa, where prevalence is far higher, the proportion of older persons losing an adult child to AIDS will be far greater.

The Thai Setting

The AIDS epidemic. Thailand's AIDS epidemic began in the 1980s and by the mid-1990s large numbers of Thais were becoming ill and dying (Rhucharoenpornpanich and Chamratrithirong 2001; TWG 2001). By the end of 2001, cumulative numbers of HIV/AIDS approached 1 million and over 300,000 had died Although an effective campaign to combat the epidemic has reduced incidence, it is projected that deaths will hover around 50,000 a year for the next decade (Phoolcharoen et al. 1998; UNAIDS 1998). The 2 percent adult prevalence level is modest compared to the worst hit African countries, but 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 1998).

As in most moderate and high prevalence countries, heterosexual intercourse has been the dominant route of HIV transmission in Thailand (UNAIDS & WHO 2000). Much of the epidemic has been driven by commercial sex patronage, a relatively unstigmatized behavior in Thailand, at least until the AIDS epidemic became serious (Knodel et al. 1996). More recently, infected men are spreading HIV to their wives and non-commercial partners (Chitwarakorn et al. 1998), with the result that women now account for almost half of new infections (TWG 2001). The lack of widespread stigmatization of the behaviors leading to infection remove one potential barrier to turning to parents for assistance and care (VanLandingham, Im-em and Saengtienchai 2002). Reasonable accurate knowledge of AIDS is relatively common among both younger and older adults, a factor that likely helps reduce negative community reaction to persons with AIDS and their caregivers (Im-em et al 2002).

Socioeconomic and demographic background. During much of the period associated with the AIDS epidemic, Thailand experienced rapid economic growth that had begun several decades earlier. However, Thailand was hard hit by the Asian economic crisis that came to a head in mid-1997 (Gragnolati 2001; UNDP 1999). Considerable government effort was made, with assistance from international donor and development organizations, to mitigate the impact of the economic crisis on health and social welfare. Specific efforts targeted the maintenance and even expansion of public low-cost health insurance and social welfare programs aimed at the most vulnerable.

Exchanges of support and services between parents and adult children are pervasive in Thailand as in much of the developing world (Knodel, Chayovan et al. 2000; World Bank 1994). Widespread norms supporting filial obligations to parents underlie the existing system of intergenerational relations (Knodel, Saengtienchai, and Sittitrai 1995). At the same time, parents typically feel a continuing obligation to ensure their children's well-being. As part of this system, living arrangements of older aged parents and adult children are closely linked. In Thailand, approximately a fourth of adult children with a parent aged 50 or more coreside with parents and another fourth live in the same community. Moreover, adult
children who live elsewhere commonly maintain contact, with almost 90 percent visiting parents once a year, two-thirds of whom visit at least several times.[1]
Fertility levels in Thailand have fallen sharply over the last several decades, declining from approximately 6 to 2 births per women (as measured by the total fertility rate) between the late 1960s and the early 1990s. Since then fertility has remained low and is currently below the replacement level (United Nations 2001). This past trend 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.

Health and social protection. Thailand has an extensive and well-functioning public health system for a developing country. Local health stations and district hospitals are widely accessible. Medical care is free for the indigent and the elderly (persons age 60 and over), and affordable health insurance has been available through several government programs, most notably a voluntary low-cost health card system that entitles household members access to government health services. This latter program is being replaced by a newly implemented program to provide universal inexpensive coverage. 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. Prior to late 2001, however, none of the government health insurance schemes covered antiretroviral therapy (ART) for HIV, although this in the process of change.

As part of the Thai government's effort to deal with the AIDS epidemic, the Ministry of Labor and Social Welfare instituted welfare programs specifically directed at persons with AIDS and their families. The forms of assistance vary, as do criteria for eligibility. The program targets infected persons generally, infected or affected women, infected heads of households, infected laborers, and children of infected persons. A group that is not targeted and that receives virtually no assistance is the older-aged parents of persons with HIV/AIDS. In addition to government programs, numerous NGOs have programs designed to assist persons with AIDS. The actual number of cases reached by these programs, however, is low compared to government programs (Im-em and Suwannarat 2002).

Among the current cohort of older Thais, few besides those who were civil servants or government enterprise employees are entitled to pensions or retirement benefits (Knodel Chayovan et al. 2000). A small monthly government allowance is available for indigent elderly through the welfare system. A mandatory social security system for employees of private enterprises was initiated in 1990 and entitled members to health insurance. Only in 1998, however, did the scheme expand to incorporate old-age benefits, and because full entitlement to these benefits will be available only to those who contributed for 15 years, the current and upcoming cohort of elderly Thais will not benefit. Moreover, at present the majority of working-aged Thais are not part of any existing scheme designed to provide retirement benefits.

Data Sources

Our analysis draws on three data sets collected using different methodological approaches as part of a comprehensive study of the impact of the AIDS epidemic on older persons in Thailand: interviews with key informants about individual AIDS cases and their families; direct survey interviews with AIDS and non-AIDS parents; and open-ended interviews with AIDS parents (VanLandingham et al 2000). The first two methods yield quantitative data and the third provides qualitative data. A brief description of each data source follows; details of the methodology are available elsewhere (Knodel, Saengtienchai, et al. 2000; Saengtienchai and Knodel 2001; Knodel et al., 2002).

Key informant study. In 1999, staff of local health centers and other informants knowledgeable about individuals who were living with or had died of AIDS in their community were interviewed in 85 rural and urban sites in 8 provinces throughout Thailand and in Bangkok. The provinces were chosen to represent a range of situations, including differing HIV prevalence levels (ranging from an average of 1 to 8 percent among army recruits during 1991-2000). The data provide basic information on living arrangements and caregiving for all cases covered and more detailed information about economic and social impacts for a subset of cases the informants knew best. Analysis is restricted to the 768 cases of adults who died in these communities, including 258 for whom supplemental information was also collected.

Direct interview survey. In 2000, face-to-face interviews using a structured questionnaire were conducted with parents of 394 persons who had died of AIDS within the prior three years, and a comparison group of 376 parents of similar ages and backgrounds who did not experience any recent death among their children. Interview sites were in three provinces in different sub-regions characterized by a range of epidemiological and economic circumstances. If both parents were alive and living together, some questions asked about each parent separately (generating information for 649 AIDS parents and 621 non-AIDS parents). The survey asked about costs associated with the treatment, funeral, and dependents of the person with AIDS, and about sources for covering these expenses. Local health personnel served as intermediaries in identifying and contacting respondents. Given the role played by intermediaries, it was impractical to assemble all information necessary to precise response rates. Based on debriefings with the intermediaries and records of interviewers, however, it appears that the large majority of potential respondents who were initially identified agreed to be interviewed (Knodel et al. 2002).

Open-ended interviews. During 1999, 19 open-ended interviews were conducted with AIDS parents in three provinces and Bangkok. The interviews cover many of the same issues as the direct interview survey, but allowed interviewees to elaborate on the issues and circumstances affecting them. All interviews were recorded and fully transcribed.

Comparison of sources. Collecting accurate and representative information about parents of persons with AIDS presents imposing methodological challenges. Any single approach is likely to be prone to some type of bias. Our open-ended interviews are based on a small number of cases and thus can only be 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 results cannot be generalized in any rigorous fashion. In addition, each of these quantitative sources has strengths and weaknesses. For instance, in comparison to information from the key informant study, which is provided by a proxy, information from the direct interview survey yields more detailed and precise information for individual AIDS parents and their deceased children. The key informant study, however, as elaborated below, is likely more broadly representative of AIDS parents generally. By adopting a multi-method approach, we believe we have generated complementary data sets that

provide a reasonably comprehensive and accurate portrayal of the economic impact on parents of losing an adult child to AIDS.

In the direct interview survey, intermediaries identified local parents who had lost an adult child to AIDS. They could generally identify parents whose children died locally, since such deaths are typically known, especially to health personnel, but had difficulty identifying parents whose children died elsewhere. Since the latter are less likely to provide caregiving and probably are less vulnerable to some potentially adverse economic and social impacts, their under-representation skews the overall sample toward parents who were involved with caregiving and support of their child during the period of illness. In contrast, the key informant study referred to all adults in the local community who were currently symptomatic or who had died of AIDS, regardless of whether their parents were alive or if they lived locally or elsewhere. Also unlike the direct interview survey, inclusion of a case did not depend on the willingness of a parent to be interviewed. The bias inherent in the direct interview survey is evident from the higher percentage of cases in which a parent was a main caregiver compared to the key informant study (71% versus 59%). However, although the overall direct interview sample is skewed towards parents who were involved in caregiving, there is little reason to expect that the sample is unrepresentative for this large subset of AIDS parents.

Despite these differences, the age distributions of AIDS parents in both quantitative sources are very similar, with approximately half aged 60 or older and most of the rest at least age 50. In addition, the AIDS cases reported in both sources have reasonably similar age, gender, and marital status distributions to Thailand's overall caseload, as represented by the national AIDS registry (Knodel and VanLandingham forthcoming-b; Knodel Saengtienchai et al. 2000).

Some clarifications. Living and caregiving arrangements of persons with AIDS often change during the course of illness. Some who live elsewhere at the onset of symptoms may return to their place of origin once they can no longer earn a living or need care assistance. Thus the extent of parental caregiving and other forms of support during illness are fully evident only after the adult child has died. Moreover, as Figure 1 made clear, the full extent of other economic impacts are manifest only after the death of the child. We thus limit analysis to AIDS parents whose children already died. Nevertheless, our data cannot capture any truly long-range impacts, given that the deaths were fairly recent, nor can we determine which of the impacts observed may dissipate with additional time.

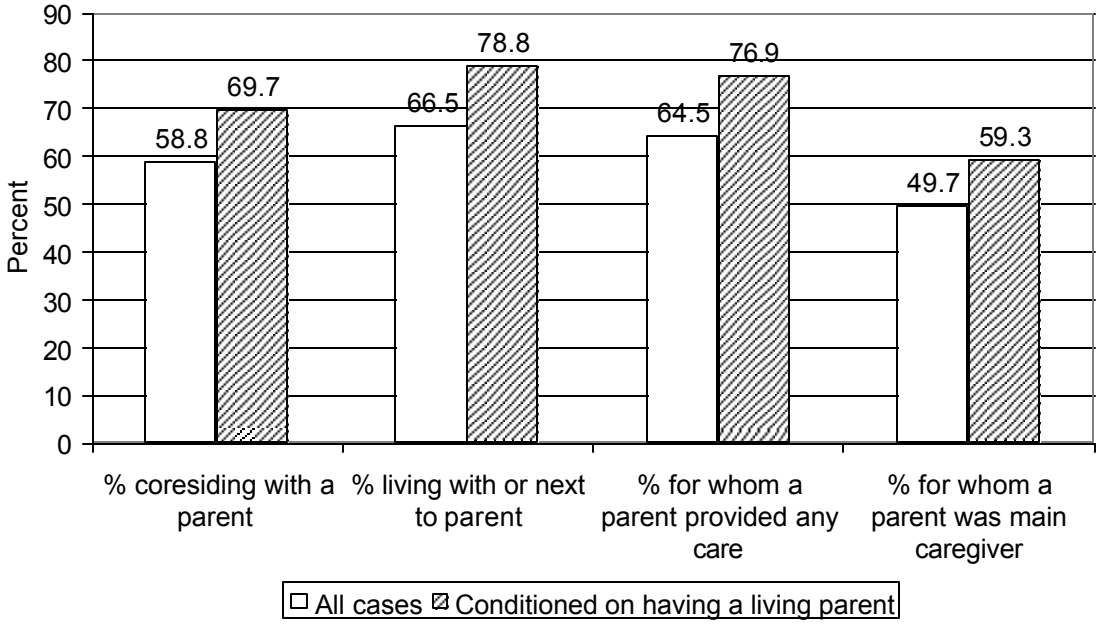
The unit of analysis in the results presented below varies with the issue being addressed. Some analyses refer to the person who died of AIDS while others refer to their parents, family, or orphaned children. For convenience, we use the term *case* to refer to the unit of analysis being described. Because many questions refer to the mother and father jointly, and because we focus on one deceased adult child per interview, AIDS parents and adult children often are interchangeable as cases.

Results

Caregiving and living arrangements

Older Thais tend to be extensively involved with their AIDS-infected adult children through both living and caregiving arrangements. This involvement has important implications for their contribution to treatment and care expenses. Figure 2 (based on key informant study results) indicates that the majority of adults who died of AIDS (59%) coresided with a parent at the terminal stage of the illness and two-thirds either coresided 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.[2] If consideration is limited to adult children with at least one living parent, the results are even more striking.[3]

Figure 2. Living and caregiving arrangements at terminal stage of illness for adults who died of AIDS (source: key informant study)



The high prevalence of parental terminal stage AIDS caregiving is related to the fact that many adult children live with or nearby the parents even under normal circumstances, which facilitates parental involvement if they fall ill. In addition, return migration of seriously ill adult children, especially in cases of a fatal and incurable disease, is common in the Thai context (Williams et al. 1996). Both the key informant study and the direct interview survey indicate that a substantial share (between a third and two-fifths) of adult children who were cared for by parents at the terminal stage had returned home from elsewhere (Knodel and VanLandingham forthcoming-b). According to the direct interview survey, of the returning adult children who were cared for by a parent, almost one fifth died within a month and almost half died within three months of their return (results not shown). These findings indicate that most return at a late stage of illness. On average, the period of serious debilitating illness, and hence parental caregiving, is no more than a few months regardless of migration status. Results from the direct interview survey indicate that parental caregiving averaged only 2.9 months and, in less than a fifth of the cases, lasted 6 months or longer. The moderate duration of parental caregiving reflects the combination of short survival times after the onset of AIDS in Thailand and attempts by many adult children to care for themselves as long possible. However, because caregiving occurs during the most disabling stage of the illness, it is likely to be emotionally and physically draining for both parent and child (Kespichayawattana and VanLandingham. 2002; Knodel and Saengtienchai 2002).

Care and treatment expenses

Illness and death from AIDS can entail an array of expenses and divert substantial time of the caregivers away from income-generating activities, thus immediately impacting the financial well-being of parents involved in supporting their sick children. Table 1 illustrates the level of parental involvement in the care and treatment expenses of their adult child who died of AIDS, based on the direct interview survey. Results are shown according to the role played by parents as personal caregivers as well as according to their economic status.[4] Because the sample is skewed toward cases in which the deceased child lived near or with parents at the terminal stage of illness, overall results overstate the level of involvement compared to AIDS parents generally. However, results for parents who were involved in caregiving may be typical of this substantial subgroup. Also, there is no obvious reason why the pattern of the relationship with economic status would be distorted.

Table 1. 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	Aver-age	Poor
N of cases	394	113	281	75	131	187
% of adult children for whom:						
A parent helped pay expenses during adult child's illness						
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***
A parent was a main contributor to expenses during adult child's illness	62.6	38.9	72.2***	71.6	67.2	55.4*
A parent helped pay for:						
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)						
All cases						
Mean	33871	28569	35977	70590	32977	19437***
Median (a)	7500	3000	10000	20000	15000	3000
Parent was a main contributor to expenses						
Mean	48119	62767	44845	90205	42147	31312**
Median (a)	20000	15000	20000	30000	20000	9250

Source: Direct interview survey

* Significant at $p \leq 0.05$ **Significant at $p \leq 0.01$ ***Significant at $p \leq 0.001$

(a) Significance tests not performed.

Among our sample, parents helped pay expenses for treatment and care during the period of illness in 82 percent of the cases and they contributed a substantial amount (defined as 5000 Baht or more) in over 61 percent.[5] For over three-fifths (63%) of the cases, a parent was a main contributor to expenses during the period of the child's illness.[6] When a parent served as a main personal caregiver, parental involvement in expenses is substantially higher than when parents did not take on a main caregiving role. Economic status is also related to paying expenses for care and treatment. Poorer parents were significantly less likely than those of average or better off economic status to contribute to expenses and particularly less likely to pay a substantial amount or to be a main contributor.

Table 1 also indicates 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 the majority of cases parents also helped pay for medicine, medical services (including hospital fees), and transportation (presumably to health facilities). A higher proportion of parents contributed to these types of expenses in cases where they served as a main caregiver than in cases where they did not. And, in comparison to parents of average or better off economic status, a smaller percentage of parents with lower economic status contributed to each of these aspects of care and treatment.

Questions about parents' contributions to expenses in the key informant study are somewhat different from those in the direct interview survey. Still a rough comparison of results is possible. 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 the 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).

By combining information in the direct interview survey on contributing to medicine, medical services, or hospital fees, we can derive a measure roughly equivalent to paying for treatment as stated in the key informant study. The direct interview survey indicates that 64 percent of all cases reported contributing to one or more of these expenses (results not in table), a figure that is substantially higher than the 52 percent from the key informant study.[7] The difference between the two sources probably reflects the expected upward bias in parental involvement in the direct interview survey. However, based only on cases in which a parent was a main caregiver in the key informant study, the percentage that contributed to treatment expenses rises to 63 percent. This is reasonably close to the equivalent result of 69 percent from the direct interview survey, especially since the question in the key informant study refers to "substantial" expenses rather than any expenses. Again, this suggests that the direct interview survey yields relatively unbiased results for the large group of AIDS parents who become involved in the care of their ill son or daughter.

Table 1 also indicates the total amount respondents in the direct interview survey reported they spent for care and treatment.[8] Since responses are skewed, we present both mean and median values. Despite substantial differences between the mean and median values, the patterns of association with the caregiving role and economic status of parents are usually quite similar. Parental involvement as a main personal caregiver is associated with greater parental expenditures than when a parent was not a main caregiver, although the difference in means in not statistically significant. Also, among cases in which parents were main contributors to expenses, the relationship between caregiver role and the amount spent on care and treatment is inconsistent, depending on whether the mean or the median is examined. In contrast, economic status is clearly associated with the amount parents paid for care and treatment, both for all cases and for 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.

The open-ended interviews with AIDS parents shed additional light on parental expenses for care and treatment. Increased costs of daily living were mentioned in half of the open-ended interviews. One common source of this was buying expensive special foods that would normally not be bought or would otherwise be bought less frequently. These foods might be bought to please the AIDS-inflicted person or because of presumed health benefits. Household food consumption and food expenses also increased if the ill child moved in from elsewhere.

> 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]

Doctors' fees, medicines, and hospitalization expenses associated with modern health care could be very substantial. Some of the better off parents took their AIDS-inflicted child to private hospitals where fees were very high. Some parents also bought expensive traditional medicines. 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 painkillers... 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, much of the health care expenses were covered through government health insurance or some welfare measure if the family was poor. This moderated the financial strain imposed on the parents. Medicines were sometimes purchased from NGOs 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 generally could afford to do so without causing them great hardship. Others had some or most of the health care costs covered through government insurance or welfare. Yet 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 subsidized, were cited as sources of financial hardship that typically led to debt.

Opportunity costs of caregiving

Besides direct expenditures, caregiving may entail opportunity costs by diverting time from income-generating or other activities of economic value. As results from the direct interview survey in Table 2 show, 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 for those in which a parent was not. Also the lower the economic status of the parents, the higher the percentage reducing their work, although the association with economic status does not attain statistical significance.

These estimates are considerably higher than those from the key informant study, which found 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 between the studies may reflect the fuller knowledge AIDS parents have about their own activities compared to the key informants.

Among married couples in the direct interview survey, about one-fourth of the cases reported that both parents curtailed economic activities and another fourth reported only one parent did. Under the latter circumstances, mothers were more likely than fathers to divert time from economic activities, reflecting the far greater tendency for mothers to be main caregivers (Kespichayawattana and VanLandingham. 2002).

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 is skewed, however, 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, although the difference is not statistical significant. The duration of time taken away from normal economic activities varies little by economic status.

Table 2. 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	Aver-age	Poor
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)	3.2	2.3	3.3	3.2	3.3	3.0
median duration (in months) (b)	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:						
Amount of forgone income (c)						
mean (in Baht)	8604	4265	9497	11318	8701	7595
median (in Baht) (b)	2500	2500	3000	6750	2500	2500
% forgoing 5000+ Baht	41.4	22.2	44.9*	60.7	38.6	36.4
Extent to which curtailment of economic activity created a financial hardship (% distribution)						
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.

* Significant at $p \leq 0.05$ **Significant at $p \leq 0.01$ ***Significant at $p \leq 0.001$

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

(b) Significance tests not performed.

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

Respondents estimated 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 modest. However, forgone income is substantially greater among cases in which a parent served as a main personal caregiver than when a parent did not. Poorer parents estimates of the value of time they lost are less than those of average or better off parents, probably reflecting the lower wages and income of those in the lower economic status category. If one or both spouses reported curtailing their economic activity, they were asked if this had created financial hardship for their household. A substantial majority said it caused at least some hardship but only just over a third felt it created a lot. Cases in which a parent was a main personal caregiver were, if anything, less likely to feel 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.

The open-ended interviews make clear that parental caregiving was typically very time consuming, particularly during the final stages of illness. 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 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]

The type of adjustment parents made to accommodate the demands of caregiving depended on the economic status of the family, the type of work they did, 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 intensive caregiving was required and spend full time with the ill child. This was made easier if someone else could take over their work or if others in the household were still earning income.

> It's a mother's responsibility… 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, working in a family business, or a day laborer hired out on a job-by-job basis. Parents who had regular outside employment, even when they were the main caregivers, did not tend to 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... 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]

Also, some parents who were quite poor could not afford to stop working, even if they took on the main responsibility for caregiving. They too worked 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 are important social events in Thailand that reflect on the prestige and reputation of the family within the community. They typically last at least several days and involve treating guests to refreshments or meals. The expenses are incurred all at once, unlike costs of care and treatment that may be spread out over the period

of illness. However, those attending funerals customarily contribute towards expenses. Also membership in local funeral societies is common as a form of insurance that provides members a lump sum benefit when a death in the family occurs (Bryant and Prohmmo 2002). Nevertheless, as Table 3 shows, parents incurred net funeral costs in almost three-fourths of the cases and in over 60 percent had substantial net costs. Both situations were more common for cases in which a parent was a main caregiver. This may reflect a greater availability of others besides a parent to cover the funeral expenses in cases where others were also available to provide the main care. Poorer parents were somewhat less likely than better off parents to have a net cost, particularly a substantial one, probably reflecting their inability to afford an expensive funeral.

Table 3. 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	Aver-age	Poor
N of cases	394	113	281	75	131	187
A parent helped pay for the funeral						
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)						
All cases						
Mean	18193	14298	19729	29154	20505	11611***
Median (a)	10000	2750	10000	16000	15000	5000
Parent paid at least some						
Mean	24488	22468	25134	38361	24682	17276***
Median (a)	15000	15000	16000	30000	20000	10000

Source: Direct interview survey
* Significant at $p \leq 0.05$ **Significant at $p \leq 0.01$ ***Significant at $p \leq 0.001$
(a) Significance tests not performed.

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 were somewhat greater when a parent was a main caregiver than when parents did not assume this role, although the difference is not statistically significant and is much reduced when conditioned on those parents who paid at least some of the funeral costs. A clear relationship between economic status and the net amount paid for the funeral is apparent. As with care and treatment costs, the amount spent on 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. Locally organized funeral insurance societies to which the family or person who died had contributed as a member sometimes covered most costs. Donations made by those attending the funeral were also important. Contributions occasionally came from charities. Occasionally, the parents actually received more than they spent. But usually they ended with substantial loss.

> 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… 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 costs of care, treatment, and funerals, not all AIDS parents were able to cover these expenses from cash in hand or savings. Table 4 shows some of the ways parents raised money to cover costs, based on the direct interview survey. Results are presented 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 to help cover expenses. This agrees reasonably well with 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 et al. 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 than mothers to take on extra work, although in a substantial share, extra work was taken on by both parents.

Table 4. 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	Aver-age	Poor
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:						
Amount borrowed (in Baht)						
mean	27103	22014	28638	44391	28898	20956*
median (a)	15000	15000	15000	30000	20000	10000
% still in debt	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
Amount received for sold property or possessions						
mean	154721	88127	168913	264882	268550	41982
median (a)	10000	7000	11300	24000	14000	10000

Source: Direct interview survey

* Significant at $p \leq 0.05$ **Significant at $p \leq 0.01$ ***Significant at $p \leq 0.001$

(a) Significance tests not performed.

-- = less than 10 cases

A more common means of meeting expenses was borrowing money. In almost two-fifths (39%) of the cases, a parent borrowed money for this purpose. Borrowing money was twice as likely when a parent was a main contributor to the expenses compared to when this was not the case. Economic status is inversely related to the portion that 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, and increased with economic status. Only about a third of the cases that borrowed to meet expenses had not yet fully paid the debt off by the time of the survey. Lingering debt was more common for those who were main contributors to expenses than for those who were not, but shows no consistent association with economic status.

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 that did so are inversely associated with economic status, with poorer parents being most likely to sell something to meet expenses. The most common possession sold was gold or jewelry. About a fourth of those who sold something to cover expenses sold land while just under a fifth sold a some sort of vehicle (not shown in table). 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. The amounts received, however, were lowest for parents who were poor.

The burden of meeting expenses associated with the illness and death of an adult child with AIDS does not necessarily fall on parents. According to the key informant study, in just over half of the cases parents made substantial contributions to treatment expenses for persons who died of AIDS and had at least one living parent (Knodel, Saengtienchai et al. 2001). Moreover, even when parents are main contributors, others may also help with the expenses. Given that the direct interview survey is skewed towards cases of parental involvement, it is not an appropriate source to judge the role of parents compared to others in covering expenses. However, it can provide a picture of who helped contributed to expenses in relation to the parents' role in paying expenses.[9]

Table 5. 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 main contributor	Parent was not main contributor (a)	
	% making any contribution	% making any contribution	% making a main contribution
Self	17.6	41.1	35.6
Spouse	13.1	24.0	17.8
Parent	100.0	52.7	0.0
Any child	0.0	0.0	0.0
Any sibling	28.7	54.8	43.2
Brother	13.5	32.2	16.4
Sister	24.2	42.5	32.2
Other male	2.5	4.8	3.4
Other female	1.6	2.7	1.4
Other, sex unspecified(b)	3.3	8.9	5.5
% of cases in which persons other than a parent contributed	52.9	100.0	100.0
N of cases	240	150	150

Source: Direct interview survey.
Notes: (a) includes cases in which parents did not contribute to paying expenses
(b) Includes place of employment, NGOs, etc.

As Table 5 indicates, 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 more commonly than brothers. The adult child who died also often helped pay for the expenses, and, among those who were married at the time of death, spouses often helped. For deceased adult children who were currently married at the time of death, spouses helped in almost a third when the parents was a main contributor and in almost half of the cases when a parent was not (results not shown in table).

The open-ended interviews provide insights into the diverse means parents used to meet the expenses. Only in a few of the economically worst-off cases did the parents mention that they had to increase the time spent working to meet the additional financial burden created by caregiving or by the loss of income that the ill child had 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 anything other people hired him to do.
> [67 year old mother, Chiang Mai, Poor]

In several in-depth interviews, parents reported selling valuables to cover the expenses associated with their child's illness and death, but these were not usually productive assets on which their income depended. Most commonly they sold gold jewelry. In one case the parents sold 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 but would not have affected their current income. Indeed, it was likely intended for situations such as they faced when their child became ill. Thus, its sale might have detracted from a sense of future security but probably not affect 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 we interviewed in-depth had few assets of value that they could sell. However if they took on serious debt to cover the expenses of treatment, caregiving, or the funeral, it could result in lasting economic hardship. In at least one open-ended interview, this was mentioned. Multiple deaths could also compound the impact even if the family had some savings before.

> It was such a mess. I didn't know what to do. I borrowed from this house or that house... I had to dig potatoes to give back their money. There were a lot of expenses… 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]

> 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]

> 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]

Formal channels of assistance.

Besides family and friends, health insurance and social welfare programs are available in Thailand and provide formal channels through which the financial burden associated with AIDS can be eased. As Table 6 indicates, in approximately three-fifths of all cases covered by the direct interview survey, some form of health insurance helped pay 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. 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.

Table 6. 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	Aver-age	Poor
N of cases	394	144	242	75	131	187
Heath insurance						
% of cases in which health insurance helped paid for medical costs	59.6	55.6	61.6	50.7	62.0	62.0
Among cases for whom insurance helped pay medical expenses:						
Type of insurance used (% distribution)						
household health card (purchased)	50.4	41.3	55.7	47.4	60.0	44.7***
low-income insurance (provided free)	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
Extent to which insurance helped with expenses (% distribution)						
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)						
% of cases that received welfare payments	18.8	15.4	20.7	14.9	14.0	23.9
Among cases who received welfare:						
A*mount received*						
mean	10342	13704	9095	3818	22416	7086*
median (b)	4000	4500	4000	4000	6000	3700
Extent to which welfare helped with expenses (% distribution)						
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.

* Significant at $p \leq 0.05$ **Significant at $p \leq 0.01$ ***Significant at $p \leq 0.001$

(a) Welfare payments include assistance from NGOs.

(b) Significance tests not performed.

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 health card scheme in which households not covered by other programs can purchase membership for a modest amount. In addition, a substantial share was covered through free health insurance for low-income households. The level of coverage for the sample is considerably higher than for the general public, in large part because the fact that a person was ill with AIDS would prompt government health providers to issue a low-income card provided the person met the criteria.[10] The percentage of cases covered by low-income insurance is inversely related to the economic status of the parents, while the reverse is true for the percentage receiving coverage by civil service or social security benefits.

Responses to a question about the extent to which the health insurance helped with expenses indicate that these schemes were of considerable assistance. In only 10 percent of the cases for which health insurance was used did the parent report it was of little help. In contrast, for more than half (56%) of those who received some coverage through insurance, the parent indicated that it helped a great deal. Although not statistically significant, the extent to which insurance helped a great deal is inversely related to the economic status of the parents. Even better off parents, however, reported that the insurance substantially helped in almost half of the cases.

A considerably smaller share of cases received some sort of AIDS welfare assistance, almost all which came through the government rather than NGOs. Receipt of assistance was substantially higher among cases in which the parents were poor than among others. These payments were typically made to the person with AIDS, but presumably also benefited parents who contributed to expenses, as it would lessen the amount that they had to pay themselves. In general, the period during which welfare was provided was often rather short. For example, in over two-fifths of the cases, payments were received only once or for no longer that a month (results not shown). 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.

The amounts received as welfare assistance were relatively modest compared to typical total expenses involved in care, treatment, and funerals. Although 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). 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 it 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 amounts paid for care, treatment, and 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 76,000 Baht. In the provinces in which we conducted our survey, the equivalent figures were 30,000 Baht in Phichit, 54,000 in Chiang Mai, and 223,000 in Rayong (UNDP 1999). According to the direct interview survey, the combined costs paid by AIDS parents for the care, treatment, and funeral of their adult child averaged 37,000 Baht both in Phichit and Chiang Mai and 97,000 Baht in Rayong (among cases in which the parents incurred any direct costs themselves, results not shown).

As Table 7 shows, when asked how serious a burden those combined expenses were for them, approximately a third of all respondents indicated that they were a serious burden. Among those who paid at least something for care and funeral expenses, the figure rises 38 percent. When a parent was a main contributor to care and treatment expenses, over two-fifths (42%) of respondents said expenses were a serious burden. Finally in cases in which a parent was both a main contributor to care and treatment expenses and had net funeral expenses, the portion for whom expenses were a serious burden approaches a half (46%).

Cases in which a parent was a main personal caregiver are far more likely to report that the care, treatment, and funeral expenses were a serious burden. Economic status is also clearly related to whether or not expenses

Table 7. 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	Ave-age	Poorer
From direct interview survey						
N of cases	394	113	281	75	131	187
Extent to which care and funeral expenses were a serious burden (percentages)						
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						
N of cases (a)	199	69	128	45	92	51
Among cases with a living parent, percentage whose parents' economic status noticeably worsened since the time of the adult child's illness	19.6	13.0	23.4	6.7	19.6	31.4**

* Significant at $p \leq 0.05$ **Significant at $p \leq 0.01$ ***Significant at $p \leq 0.001$
(a) total includes cases with missing values on caregiver status and economic status.

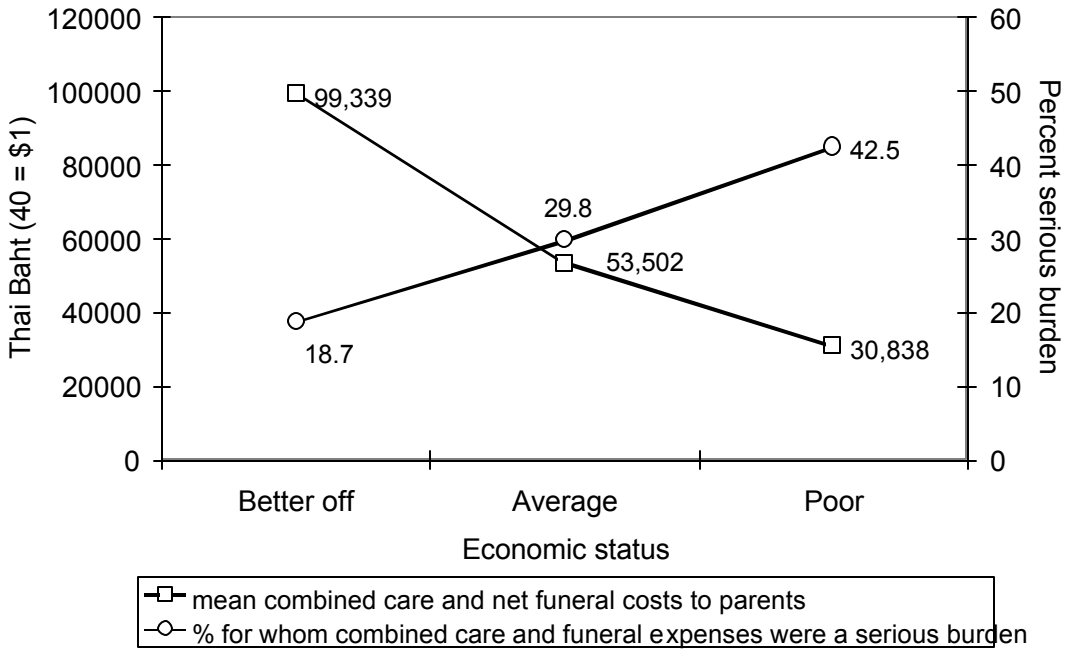
were a burden, with poor parents more than twice as likely to say so than the better off group. Over two-fifths (43%) of poor parents reported the care and funeral expenses as a serious burden. This reaches over three-fifths of the cases in which a parent of poor economic status was a main contributor 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. As Table 7 shows, in a fifth of the cases overall, 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 a clear inverse association between the parents' economic status and the percent whose economic situation worsened.[11]

We also performed logistic regression based on the direct interview survey with the dependent variable being whether or not the combined expenses of caregiving, treatment and the funeral were reported to be a serious burden (results not shown in table). Both being a main contributor to expenses and paying net funeral costs when entered together as covariates show highly statistically significant associations with the overall expenses being a burden, indicating each contributes independently to the financial strain experienced by the parents.[12] In addition, stopping work for caregiving, selling possessions, and borrowing money when entered together as covariates are each associated with expenses being a burden, but only selling possessions and borrowing money yield statistically significant coefficients.[13] Thus these two adverse outcomes for parents of having an adult child with AIDS appear independently to contribute to the overall economic burden experienced

Figure 3, based on results from the direct interview survey, makes clear that both expense associated with having an adult child die of AIDS and adverse economic impact have pronounced associations with economic status – but in opposite directions. Lower economic status is associated with lesser amounts spent but with higher percentages of parents who felt the expenses 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 to their resources. A similar pattern is evident from the key informant study results, which indicate that the percentage of cases for which care and treatment expenses were substantial (although not explicitly for parents) was inversely related to the parents' economic status prior to the adult child's illness (results not shown, see Knodel, Saengtienchai et al. 2001).

Figure 3. Mean combined care and net funeral costs to parents and percent for whom costs were a serious burden (source: AIDS parents survey)



The open-ended interviews reveal considerable variation in the extent that expenses associated with caregiving, treatment, and funerals created financial strain on AIDS parents. For some, the strain was great. In these cases, not only were the parents quite poor to start, so that even modest absolute expenses were a burden, but in a couple of cases there were at least two persons with AIDS involved. Most parents who borrowed, however, reported they were able to clear the debt later. For many other cases, however, the financial strain on parents appeared to be only moderate and in several cases, financial strain was 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. In other cases, parents found ways to moderate how much they had to pay themselves. Some families pooled resources or took advantage of formal channels of assistance. Moreover, most cases adjusted what they spent, at least to some extent, to their circumstances. In addition, some adult children with AIDS had income or savings of their own that helped cover treatment costs and other expenses.

> 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]

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 following the death of their son or daughter. For those who spent within their means, economic hardship would be short lived. If these expenses seriously deplete savings, incur substantial debt, or cause sale of assets, however, longer term repercussions could also result. In addition, AIDS parents who take responsibility for surviving dependents of their deceased son or daughter could continue to incur costs for years. Sustained adverse economic consequences could also result from the loss of

support that the deceased adult child had been providing or would have provided in later years of life. The direct interview included questions to assess expenses for dependents of the child who died and lost filial support. 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. Assistance by AIDS parents to either grandchildren or sons/daughters-in-law may start during the period when their own adult child is ill or after the death. If the deceased child was not married or had no dependent children, however, this potential source of economic impact is absent. According to the national AIDS registry in Thailand, about a third of adults who have AIDS never married (and thus almost certainly are childless) and almost a tenth are widowed, divorced, or separated (Knodel and VanLandingham forthcoming-b). A similar proportion (approximately 30 percent) of the AIDS cases covered by both the key informant survey and the direct interview were never married. The proportions widowed, divorced, or separated, however, are higher (21 and 25 percent respectively), perhaps reflecting at least in part substantial martial dissolution between AIDS diagnosis and death (since our sources focused mainly on adults who had already died). Consistent with the prevailing recent low fertility in Thailand, some who were or had formerly been married at the time of death had no children, and those who did usually had only one.[14] According to both the key informant study and the direct interview survey, only 44 percent of the AIDS parents had an orphaned grandchild to be cared for.

As Table 8 shows, in almost a third of the cases covered by the direct survey, AIDS parents had assisted a dependent of their deceased child. 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, which presumably were mainly the grandchildren. Given that the direct interview survey is skewed towards cases in which parents lived with or near the deceased child during the terminal stage of illness, this estimate is likely to be biased upward compared to what would be found for a more general sample of AIDS parents.[15] At the same time, the estimate from the direct interview survey does not take into account that some AIDS parents who are not responsible financially for dependent grandchild left behind by their deceased son or daughter will eventually end up taking responsibility for them. This is especially likely since some of the dependent grandchildren not in the custody of the grandparents are with the surviving spouse, who may in turn be HIV infected and die before the dependent children grow up.

Table 8. Parental involvement in expenses related to dependents of adult children who died of AIDS

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

Source: Direct interview survey.

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 cases. This help was likely limited to the period of caregiving when the spouse of ill son or daughter was living with the respondent. 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 continue to cover expenses. In contrast, if the deceased son or daughter had children, a majority said they expected to continue support (results not shown).

Table 9. Contribution of adult child who died of AIDS to parental household

	All cases	Economic status		
		Better off	Average	Poor
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				
Among deceased children who contributed any income	13341	20280	11323	12415*
mean	6000	12000	5700	4750
median (a)				
Among deceased children who were main providers				
mean	16316	22460	15058	15951*
median (a)	10400	12000	11400	10000
Coresidence and household services				
% of deceased adult children who were coresident with a parent before becoming seriously ill				
continuously	57.6	58.7	61.8	54.0
part of time	16.0	12.0	14.5	18.7
Among coresident deceased adult children, extent of help they provided with household chores or family economic activities (% distribution)				
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.
* Significant at $p \leq 0.05$ **Significant at $p \leq 0.01$ ***Significant at $p \leq 0.001$
(a) Significance tests not performed.

The most common source of expenses for AIDS parents in connection with dependents of the deceased child was food. 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 school expenses will be covered by the AIDS parents in the future. When a spouse but no grandchildren was involved, it was relatively uncommon for the AIDS parents to incur other types of dependent expenses.

Loss of filial support. The most serious longer term economic impact for some AIDS parents is the loss of current and potential future support from their deceased child. As Table 9 shows, in over 70 percent of the parental households covered by the direct interview survey, the deceased child was providing material assistance to the parents before their illness, and in almost a third had been the main income provider. These overall proportions may be inflated by the likelihood that the sample is skewed toward parents who were living with or nearby the deceased child even before the child became ill. 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.

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, particularly when the deceased children was the main provider. The contributions to economically better off parents were greater in absolute amounts than to those of lower economic status. 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 9 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 in almost half (48%) had provided regular assistance. The extent of regular assistance is particularly high among parents who were poor.

Respondents were asked if someone else moved in following the death of their adult child to assist with support and maintenance of the household. Only a minority of respondents reported this to be the case. Even when the deceased child had been continuously coresident before the illness, only 8 percent of respondents reported someone else augmenting the household. Also there is little relationship between economic status and someone else moving in. It thus appears that, at least up to the time of the survey, living arrangements were not commonly adjusted to make up for the loss of a coresident adult child.

When asked to assess how difficult the loss of income or services were for their financial situation, more than half of the respondents reported that the situation was made more difficult. The percent reporting that the situation was much more difficult shows a pronounced inverse association with economic status (only 8 percent of economically better off respondents compared to 44 percent of those who were poor).

The open-ended interviews also make clear that the loss of the support from deceased children could have serious and lasting economic consequences for parents, particularly if 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]

Although a number of the deceased non-coresident adult children at least occasionally gave monetary gifts to their parents, these contributions usually were more of token significance than being crucial for the longer run economic security of the parents, although there were exceptions.

> (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]

Neither our qualitative nor quantitative data, however, can 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 support.

Comparisons with non-AIDS parents. As described above, the direct interview survey included not only AIDS parents but also similarly aged parents who did not lose a child. Comparisons between these two groups of parents with respect to their economic situation, living arrangements, and support exchanges with children, and particularly recent changes in those circumstances, should reflect any sustained intermediate-term impact of the loss of a child to AIDS. Questions in the survey referred to changed circumstances over the prior three years. We chose this reference period because, by survey design, the deceased children of the AIDS parents died with six months to three years prior to interview. We note, however, that some of these deceased adult children may have been ill even earlier than three years prior to the survey and thus some economic impacts associated with HIV/AIDS may have already been manifest at the start of the start of the reference period.

The survey design called for interviewing non-AIDS parents who were similar in age and socioeconomic background to the AIDS parents selected for interview in order to minimize pre-existing differences between two groups. Implementing an exact match, however, proved difficult. Thus the two groups do differ modestly on several potentially important dimensions (Knodel et al 2002). Compared to respondents who did not lose a child, the AIDS parents are slightly older, had somewhat fewer living children on average before the death of the deceased child, and tend to be from somewhat more disadvantaged backgrounds. For example, AIDS parents are somewhat less educated and more skewed towards poorer households (based on our measure of economic status -- see footnote 4). Although the less favorable economic status for AIDS parents could in part reflect the impact of losing a child to AIDS, their lower educational attainment, which would usually be correlated with economic status, suggests that AIDS parents were probably worse off than the other group prior to experiencing the illness and death of their adult child. To take this into account when making comparisons, we calculate adjusted odds ratios (with AIDS parents as the reference group) employing logistic regressions that include age, education, socioeconomic status, and number of adult children prior to any death of child with AIDS.[16] If, in case of AIDS parents, socioeconomic status does reflect some impact of the adult child's illness and death, the adjusted results will underestimate the impact and thus provide a conservative assessment.

As Table 10 shows, AIDS parents were more likely than the comparison group to judge their current financial status as difficult. AIDS parents were also more likely to indicate that their financial status had become much worse over the past three years. Controlling for background characteristics has little effect on the odds ratios. These results are consistent with the possibility 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, only 28 percent specifically mentioned the costs of the child's illness as the main reason (not in table). The economic downturn in Thailand associated with the Asian economic crisis might account for why substantial proportions of non-AIDS parents also reported that their financial status worsened.

Table 10. Comparison of AIDS and non-AIDS parents with regards to financial status, indebtedness , living arrange ments, household composition, and support

	AIDS parents households	Non-AIDS parents households	Odds ratios (AIDS parents as reference)(a)	
			Unadjusted	Adjusted
Financial status				
% whose current financial situation is difficult	57.1	40.8	.518***	.562***
% whose years financial situation over the past 3				
worsened at all	53.5	46.3	.747*	.795
worsened a great deal	19.5	10.4	.476***	.551**
Indebtedness				
% with very or somewhat serious debt				
currently	33.8	26.8	.721*	.684*
3 years earlier	30.5	24.0	.716*	.687*
Living arrangements/household composition				
% of households with				
a coresident adult child	65.0	72.9	1.448*	1.580**
at least one adult child in same locality	80.0	88.0	1.845*	2.499***
with a minor (under 15) in household	56.6	48.7	.727*	.722*
with a foster child in household (b)	31.5	12.8	.319***	.336***
with a double-orphaned child in household (c)	11.7	0.3	.020***	.020***
Support exchanges with children				
% of respondents who received from at least one adult child during previous year:				
1000+ Baht in cash	67.8	72.3	1.244	1.435*
material gifts worth 1000+ Baht	61.2	68.9	1.405*	1.424*
% of respondents who gave to at least one adult child during previous year:				
1000+ Baht in cash	36.8	45.5	1.432*	1.267
material gifts worth 1000+ Baht	27.9	36.2	1.463*	1.283
Change in support from children				
% receiving less support now than 3 years ago	41.9	25.9	.484***	.529***

Source: Direct interview survey.

* Significant at $p \leq 0.05$ **Significant at $p \leq 0.01$ ***Significant at $p \leq 0.001$

(a) based on logistic regression coefficients; adjusted ratios are based on regressions that include measures of age, education, economic status and number of adult children before death of child with AIDS.

Notes: (b) a foster child is a child under age 15 whose parents do no live in the same household.

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

AIDS parents were more likely than non-AIDS parents to indicate that they were currently experiencing serious debt and that they were seriously in debt three years ago. In response to an open-ended question, only about a fifth of the AIDS parents who said their debt was serious cited their child's illness as the reason for their debt, both with respect to the current and earlier debt (not in table). The fact that some AIDS parents cite their child's illness as the reason for the earlier debt suggests that, for at least some, the illness of their child had an impact even before our reference period started.

As noted, many older-age Thai parents depend on adult children within a system in which economic support is linked to coresidence with or residence nearby the adult child. At least among our sample, the death of an adult child rarely left the parents childless (fewer than 3 percent had no children left, not shown in table). AIDS parents, however, were somewhat less likely than non-AIDS parents to be coresident with an adult child or to have an adult child in the same locality at the time of the survey. Nevertheless, an adult child was present in almost two-thirds of the AIDS parents' households and for four-fifths at least one child coresided or lived locally. 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 alive) or a double-orphaned child (i.e., who has lost both parents). Adjusting for background characteristics either had little impact or strengthened the contrast with non-AIDS parents.

AIDS parents were less likely than non-AIDS parents to have received significant cash (defined as 1,000 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, although the relationship loses statistical significance once background differences are controlled.. A substantially higher proportion of AIDS parents indicated that they received less support from their children now than three years ago. When those who reported less support from children were asked in an open-ended question why support has declined , about half of the AIDS parents stated the reason was the death of their child.

Overall the results of the comparison between the two groups of parents are reasonable consistent with the rest of our analysis. Both suggest that losing an adult child to AIDS has substantial adverse consequences for economic well-being in some share of cases, but not for most.

Conclusions

Serious challenges are involved in collecting systematic empirical data on the impact of the AIDS epidemic on older persons through the illness and death of an adult son or daughter. 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 case studies can be suggestive of the situation and help identify relevant issues, it cannot ultimately substitute for broad-based and systematic evidence of the actual prevalence and nature of potential adverse consequences for economic or other dimensions of well-being.

Overall, our findings indicate that 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 membership in a local funeral society and by customary contributions by community members attending the funeral. Families sometimes pooled resources, or 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. Although 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, leading them into debt. Also disruption of normal economic activities could contribute to the burden disproportionately for 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 should 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 orphaned grandchildren.[17] An important part of the explanation is that, for over half of the AIDS parents, the deceased son or daughter had no children. In addition, each set of orphaned grandchildren are likely to have two sets of living grandparents, only one of which might take custody. When grandchildren did exist, however, grandparents were commonly involved in raising them. Moreover, some grandchildren being cared for by their surviving parent may end up with a grandparent in the future, especially if the surviving parent is HIV positive and dies.

Because insufficient time had past at the time of data collection, our research is not suitable for assessing potential long-term consequences that could arise, such as the impact of losing a potential provider of care or a

contributor to material support in old age. Other effects evident at the time of our study, however, may be shorter term and dissipate as time passes. In considering potential longer term consequences, it is relevant to consider that most current AIDS parents in Thailand have other surviving children on whom they can depend, reflecting the high fertility levels that prevailed until several decades ago. Thus the loss of just one son or daughter may not seriously jeopardize their old-age care and support from adult children.

As our conceptual framework highlighted, the particular culture, politics, and socioeconomic development of any setting, as well as the epidemiology of the epidemic, are likely to condition the nature and magnitude of the impact on older AIDS parents of the illness and death of a child. Thailand shares some important characteristics with many other countries with moderate to severe HIV/AIDS epidemics that help determine 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 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.

Endnotes

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

[2] In both the key informant study and the direct interview survey, more than one person was allowed to be designated as a main caregiver although usually only one person was so designated. For example, in the direct interview survey, among cases of parental caregiving, both parents were designated as main caregivers in 12 percent of the cases and a parent shared the role with someone other than his or her spouse 16 percent of cases.

[3] Results were adjusted for the 8 percent of cases for which the key informant did not know if the parents were alive (see Knodel et al. 2001).

[4] Household economic status is based on a combination of self assessed economic status of the respondent relative to others in the community and the interviewer's judgment based on the appearance of their house.

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

[6] 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.

[7] The figure of 64 percent is only slightly higher than the 63 percent who paid for medicine (as seen in the all cases column in Table 1 because of very high overlap between those for medicine and those who paid for medical services/hospital fees.

[8] If respondent were unable to estimate a single amount they were could provide an answer within a range which are then converted to single amounts to calculate the results in Table 1.

[9] Since the survey did not ask who paid for the funeral besides the parents, the following discussion does not take funeral expenses into account.

[10] This is made clear in a series of open-ended interviews and focus groups we conducted as another component of our research (results not yet published).

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

[12] The odd ratios are 2.17 (p=.002) and 3.19 (p=.00) respectively.

[13] The odds ratios are as follows: 1.20 (p=.45) for stopping work for caregiving; 3.04 (p=.000) for selling possessions; and 4.79 (p=.000) for borrowing money.

[14] In a few cases, the grandchildren had died before their parents, presumably in most cases from AIDS acquired through perinatal transmission.

[15] A likely upward bias is consistent with the fact that the percentage of AIDS parents who ever cared for an AIDS orphan is substantially higher in the direct interview survey than indicated by indicated by the key informant study (31 versus 18 percent) (Knodel and Saengtienchai 2002).

[16] Age and number of children are treated in the regressions as continuous variables. Education and economic status are treated as categorical variables (3 categories for education and 5 for economic status). In cases where both parents were alive and living together, the age variable was given a value equal to their mean; if the parents had unequal education, the higher of the two levels was used. Since the two groups of parents had virtually identical proportions currently married, marital status was not entered into the regressions.

[17] Interestingly, a systematic quantitative study in Zaire, found that only about a third of AIDS orphans were being cared for by their grandparents (Ryder et al. 1994).

References

Barnett, Tony, Alan Whiteside and Chris Desmond. 2001. "The social and economic impact of HIV/AIDS in Poor Countries: a review of studies and lessons" *Progress in Development Studies* 1 (2): 151-170.

Bloom, David and Peter Godwin (eds.). 1997. *The Economics of HIV and AIDS: The Case of South and South East Asia*. New Delhi, India: Oxford University Press.

Bloom, David and Joyce Lyons, (eds.) 1993. *Economic Implications of AIDS in Asia*. New Delhi, India: UNDP Regional Project on HIV & Development.

Bryant, John and Aree Prohmmo. 2002. Equal contribution and unequal risk in a North-east Thai Village funeral society. *The Journal of Development Studies* 38(3):63-75.

Chayovan, Napaporn and John Knodel. 1997. *The Survey of the Welfare of Elderly in Thailand*. Bangkok: Chulalongkorn University, Institute of Population Studies.

Chitwarakorn, Anupong, Werasit Sittitrai, Tim Brown, and Doris Mugrditchian. 1998. "Thailand." Pp. 304-38 in *Sexually Transmitted Diseases in Asia and the Pacific*, Tim Brown (ed.), Armidale, New South Wales, Australia: Venereology Publishing Inc.

Godwin, Peter (ed.). 1997. *Socio-economic Implications of the Epidemic*. New Delhi: UNDP Regional Project on HIV & Development.

Gragnolati, Michele. 2001. *The Social Impact of Financial Crises in East Asia - Evidence From the Philippines, Indonesia and Thailand*. Washington, D.C.: World Bank.

Im-em, Wassana. 1999. *Mortality Trends and Levels to Verify the AIDS Epidemic in Thailand: Analysis From Death Registration Statistics, 1984-1997*. IPSR Publication No. 239. Bangkok: Mahidol University, Institute for Population and Social Research.

Im-em, Wassana and Sasipen Phuongsaichai. 1999. *Household Resources Allocation and Response Towards AIDS-Related Illnesses*. Bangkok: Population and Society Research Institute, Mahidol University.

Im-em, Wassana and Gary Suwannarat. 2002. *Response to AIDS at Individual, Household and Community Levels in Thailand*. Geneva: UNRISD.

Im-em, Wassana , Mark VanLandingham, John Knodel, Chanpen Saengtienchai. (2002) HIV/AIDS-related Knowledge and Attitudes: A Comparison of Older Persons and Young Adults in Thailand. *AIDS Education and Prevention* 14(3): 246-262.

Kespichayawattana Jiraporn and Mark VanLandingham. 2002. "Health impacts of co-residence with and care giving to persons with HIV/AIDS (PHAs) on older parents in Thailand." Paper presented at the Annual Meetings of the Population Association of America, Atlanta, GA., 9-11 May 2002

Knodel, John, Napaporn Chayovan, Siriwan Graiurapong, and Chutima Suraratdecha. 2000. "Ageing in Thailand: an Overview of Formal and Informal Support." Pp. 243-66 in *Ageing in the Asia-Pacific Regions: Issues and Policies*, D. Phillips (ed.). London: Routledge.

Knodel, John, Wassana Im-em, Chanpen Saengtienchai, Mark VanLandingham, and Jiraporn Kespichayawattana. 2002. *The Impact of an Adult Child's Death Due to AIDS on Older-Aged Parents: Results From a Direct Interview Survey*. Bangkok: Mahidol University, Institute for Population and Social Research.

Knodel, John and Chanpen Saengtienchai 2002. *AIDS and Older Persons: The View From Thailand*. Research Report 02-497. Population Studies Center, University of Michigan.

Knodel, John, Chanpen Saengtienchai, Wassana Im-em, and Mark VanLandingham. 2000. *The Impact of Thailand's AIDS Epidemic on Older Persons: Quantitative Evidence From a Survey of Key Informants*. IPSR Publication No. 252. Bangkok: Mahidol University, Institute for Population and Social Research.

Knodel, John, Chanpen Saengtienchai, Wassana Im-em, and Mark VanLandingham. 2001. "The Impact of AIDS on Parents and Families in Thailand: A Key Informant Approach." *Research on Aging* 23(6):633-70.

Knodel, John, Chanpen Saengtienchai, and Werasit Sittitrai. 1995. "The Living Arrangements of Elderly in Thailand: Views of the Populace." *Journal of Cross-Cultural Gerontology* 10:79-111.

Knodel, John and M. VanLandingham. Forthcoming-a. "The impact of the AIDS epidemic on older persons. " *AIDS 2002 (Year in Review Supplement)*.

Knodel, John, and Mark VanLandingham. Forthcoming-b. "Return Migration in the Context of Parental Assistance in the AIDS Epidemic: The Thai Experience." *Social Science & Medicine*

Knodel, John, Mark VanLandingham, Chanpen Saengtienchai, and Wassana Im-em. 2001. "Older People and AIDS: Quantitative Evidence of the Impact in Thailand." *Social Science & Medicine* 52(9):1313-27.

Knodel, John, Mark VanLandingham, Chanpen Saengtienchai, and Anthony Pramualratana. 1996. "Thai Views of Sexuality and Sexual Behavior." *Health Transition Review* 6(2):179-201.

Knodel, John, Mark VanLandingham, and Susan Watkins. forthcoming. "AIDS and Older Persons: An International Perspective." *Journal of Acquired Immunodeficiency*.

Kongsin, Sukhontha, Sukhum Jiamton, Charlotte Watts, and Angsana Boonthum. 2001. "Conducting a Household Survey on the Economic Impact of Chronic HIV/AIDS Morbidity in Rural Thailand: Methodological Issues." *Journal of Health Science* 10(2):236-45.

Nelson, K. E. 1998. "The Demographic Impact of the HIV Epidemic in Thailand." *AIDS* 12(7):813-4.

Phoolcharoen, W., K. Ungchusak, W. Sittitrai, and T. Brown. 1998. "Thailand: Lessons From a Strong National Response to HIV/AIDS." *AIDS* 12 (supplement B):S123-S135.

Pitayanon, Sumalee, Sukhontha Kongsin, and Wattana Janjareon. 1997. "Economic Impact of HIV/AIDS Mortality on Households in Thailand." *The Economics of HIV and AIDS: The Case of South and South East Asia*, eds. David Bloom and Peter Godwin. Delhi : Oxford University Press.

Rhucharoenpornpanich, Orratai and Aphichat Chamratrithirong. 2001. " Demographic Impact of AIDS on the Thai population ," *Asia-Pacific Population Journal* 16 (3): 71-88.

Ryder, Robert, Munkole Kamenga, Muniaka Nkusu, Veronique Batter, and William. Heyward. 1994. "Aids Orphans in Kinshasa, Zaire: Incidence and Socioeconomic Consequences. " *AIDS* 8 (5):673-80.

Saengtienchai, Chanpen and John Knodel. 2001. *Parents Providing Care to Adult Sons and Daughters With HIV/AIDS in Thailand*. Geneva: UNAIDS.

TWG (Thai Working Group on HIV/AIDS Projection). 2001. *Projections for HIV/AIDS in Thailand: 2000-2020.* Bangkok: Thai Ministry of Public Health.

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

UNAIDS. 1999. Children Orphaned by AIDS: Front-line Responses from Eastern and Southern Africa. Geneva, UNAIDS.

UNAIDS. 2000. *Report on the Global HIV/AIDS Epidemic, June 2000*. Geneva: UNAIDS.

UNAIDS. 2002. *Report on the Global HIV/AIDS Epidemic, July 2002*. Geneva: UNAIDS.

UNAIDS and WHO. 2000. *Thailand, Epidemiological Fact Sheet on HIV/AIDS and Sexually Transmitted Infections: 2000 Update*. Geneva.

United Nations. 2001. *World Population Prospects: The 2000 Revision. Volume I: Comprehensive Tables*. New York: Unite Nations.

United Nations. 2002. *Report of the Second World Assembly on Ageing. Madrid, 8-12 April 2002*. (Publication A/CONF.197/9). New York: United Nations

UNICEF (United Nations Children's Fund). 2000. *The State of the World's Children*. New York: United Nations.

UNDP (United Nations Development Programme). 1999. *Human Development Report of Thailand 1999*. Bangkok: UNDP.

van Griensven, F., S. Surasiengsunk, and Panza A. 1998. *The Use of Mortality Statistics As a Proxy Indicator for the Impact of the AIDS Epidemic on the Thai Population.* Publication No. 267/98. Bangkok: Chulalongkorn University, Institute of Population Studies.

VanLandingham, Mark, John Knodel, Wassana Im-em, and Chanpen Saengtienchai. 2000. "The Impacts of HIV/AIDS on Older Populations in Developing Countries - Some Observations Based on the Thai Case." *Journal of Family Issues* 21(6):777-805.

VanLandingham Mark, Wassana Im-em, and Chanpen Saengtienchai. 2002. "Community Reaction to Persons with HIV/AIDS and their Parents in Thailand." University of Michigan Population Studies Center Research Report No. 02-530.

Wachter, Kenneth, John Knodel, and Mark VanLandingham. 2002. "AIDS and the Elderly of Thailand: Projecting Familial Impacts." *Demography* 39(1):25-41.

Williams, A, E. Bennet, V. Himmavanh and F. Salazar. 1996. " They just go home and die": Health care and terminal illness in rural northeast Thailand. *Asian Studies Review* 20:98-108.

World Bank. 1994. *Averting the Old Age Crisis: Policies to Protect the Old and Promote Growth*. Oxford, England: Oxford University Press.