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**AIDS and Older Persons: The View from Thailand**

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## **AIDS and Older Persons: The View from Thailand**

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## **Abstract**

Although little attention has been paid to older adults in the context of the global AIDS epidemic, they not only can contract HIV themselves but, far more commonly, they experience multiple consequences as in their role as parents of younger adults who become ill and die from AIDS. Older persons also make significant contributions to the well-being of younger adults who suffer from AIDS by playing a major role in caregiving to their infected sons and daughters and by assuming the role of foster parents for their grandchildren who are left behind as AIDS orphans emphasizing the consequences for and the contributions by older persons in their role as AIDS parents. The analysis is based primarily on interviews with key informants about individual AIDS cases and their families; direct survey interviews with AIDS parents and a comparison group of older persons; and in-depth interviews with AIDS parents. The first two permit quantitative analysis while the third is suited for qualitative analysis.

## Executive Summary

The global AIDS epidemic is typically associated with adults in their 20s, 30s and 40s and to a lesser extent with their young children who are left behind as AIDS orphans and who sometimes are infected themselves through perinatal transmission. Older adults are also very much impacted by the epidemic even though their situation has largely been ignored in the discourse about AIDS. Not only can older adults contract HIV themselves but, far more commonly, they experience multiple consequences as older generation relatives, particularly in their role as parents of younger adults who become ill and die from AIDS. Older persons also make significant contributions to the well-being of younger adults who suffer from AIDS by playing a major role in caregiving to their infected sons and daughters and by assuming the role of foster parents for their grandchildren who are left behind as AIDS orphans. In addition, older persons have considerable untapped potential for contributing to efforts to expand and improve the treatment of persons with AIDS. Very little research has been conducted so far on these issues, especially in developing world settings. One exception is the comprehensive study of AIDS and older persons that we and our colleagues are conducting in Thailand. This paper addresses the impact of the AIDS epidemic for older adults based on that research. Since parents of adults with AIDS are the most common group of older persons who experience direct consequences of the epidemic, the primary focus is on the consequences for and the contributions by older persons in their role as AIDS parents.

Our analysis is based primarily on three components of our research project: interviews with key informants about individual AIDS cases and their families; direct survey interviews with AIDS parents and a comparison group of older persons; and in-depth interviews with AIDS parents. The first two permit quantitative analysis while the third is suited for qualitative analysis.

There are several major findings from our analysis that deserve emphasis. Probably the most important is that substantial numbers of older-aged persons are adversely affected by the AIDS epidemic through the infection of their adult children. Not only do these AIDS parents far exceed the number of older persons who are HIV infected themselves but, at least in Thailand, they far outnumber AIDS orphans, a group that has received extensive publicity and attention. Yet these older-aged AIDS parents have been largely overlooked by national governments, international organizations, and private organizations concerned with the epidemic.

AIDS parents can suffer a wide variety of adverse consequences as a result their adults child's illness and death. The only aspect of the situation of AIDS parents that has received some attention, however, is in their role in fostering orphaned grandchildren. But this is only one of many pathways through which older age AIDS parents can be affected and, in contexts such as Thailand, involves only a minority of older persons among those who lose their adult son or daughter to the disease. In other settings, particularly in high prevalence African countries, where the fertility levels of those in the ages most susceptible to AIDS is much higher, care for AIDS orphans will be more common. While the care of orphaned grandchildren remains an important pathway through which the epidemic affects older persons, its extent and consequences for grandparents is likely to vary substantially with the particular setting. Moreover, the almost exclusive emphasis on older people as foster parents for AIDS orphans gives the misleading impression that this is both the most common and most significant way that older people are affected, neither of which is necessarily correct.

At the same time that older-aged parents suffer adverse impacts they also make very substantial contributions in helping the society cope with the epidemic through the care-giving of their infected sons and daughters. Our results suggest that the majority of Thai adults with AIDS live with and are cared for by a parent by the terminal stage of the illness and in half of the cases, a parent serves as a main caregiver. This is very similar to findings from Uganda, the only other country for which a systematic assessment is available. By providing care for their adult children at home, AIDS parents take a tremendous burden off the health care system. Our results also reveal that many of the adverse impacts experienced by parents are linked with their contribution as caregivers and are particularly pronounced in situations in which a

parent acts as a main caregiver. Parents also often serve as critical links between their ill adult child and the health care system. They frequently accompany their infected son or daughter to health service outlets, stay with them in the hospitals, consult with health care providers about appropriate treatment, administer the prescribed medications, and provide a full range of personal care at home. Yet at present there is little recognition in Thailand or elsewhere of this major contribution of older-aged parents. Thus almost no programs exist that are designed to provide guidance to them as they carry out this arduous and painful role.

Our in-depth interviews with AIDS parents clearly reveal the dedication with which most AIDS parents involved with caregiving carry out their role and their desperate wishes to reduce the suffering and improve the health of their infected sons and daughters. Older parents are thus ideally situated and motivated to help in efforts to improve the quality of care of persons with HIV/AIDS. Their potential contribution is likely to increase in importance as new, more ambitious programs promote more extensive prophylaxis and treatment for opportunistic infections, complex antiretroviral treatment of HIV, and palliative care.

Overall, the loss of a child to AIDS has a serious economic impact only for a minority of AIDS parents. Those parents who spent substantial amounts on treatment tend to be economically better off than average and hence can afford to do so without lasting financial hardship. At the same time, the poor appear to be the most adversely affected. Even though they spent less on treatment, caregiving and funeral expenses, the amounts were more devastating for them relative to their economic resources. One implication of this finding is that interventions intended to help older-aged parents deal with the financial strains associated with losing an adult child to AIDS should take into account the considerable range of vulnerability that exists and target those who are particularly susceptible to resulting economic hardship.

Some potential impacts of losing an adult son or daughter to AIDS, such as loss of old age support, may not become apparent until long after the adult child's death. Our research is likely to miss these potential long term effects because insufficient time had past at the time of data collection. However, most AIDS parents have other surviving children on whom they can depend. Thus for many the loss of just one adult child may not seriously jeopardize their old age care and support from adult children. If the AIDS epidemic continues on any significant scale, however, subsequent generations of AIDS parents will have had smaller families and the impact a losing even just one adult child could have a more extensive impact on support from children in old age. In some African countries, where HIV prevalence is far higher than in Thailand, parents are at much greater risk of losing multiple children and thus more vulnerable to serious erosion of potential old age support.

Sustained social stigma directed at parents of persons who died of AIDS is far from universal in Thailand at present. Sympathetic and supportive reactions from others in the community are more frequently reported than negative ones. Clearly negative reactions are not absent in many community settings and our open-ended interviews revealed many such examples. However, anecdotal evidence of extreme negative reaction, especially during early stages of the epidemic, has led to an exaggerated and out-dated view of the predominance of stigmatization and to resistance to recognizing that community members can also be sympathetic and helpful to a family unfortunate enough to lose a member to AIDS.

One implication of the relative predominance of positive community reaction is that programs designed to build on community support in order to assist families with a member ill with AIDS or who have suffered an AIDS death would meet less resistance than might otherwise be thought. A more accepting community attitude is also likely to increase the willingness of an ill adult child to return home from elsewhere and that of the parents to accept responsibility for an AIDS inflicted son or daughter.

Thailand shares important characteristics with many of countries with moderate to severe levels of the HIV/AIDS epidemic that are likely to condition the implications for parents and families. These include the heterosexual nature of most transmission and the dependence of parents on adult children for old age

support. There are also features of the Thai situation that distinguish it from many other developing countries, particularly those in Africa where the severity of the epidemic is far worse. Many of these features are likely to moderate the impact of the epidemic on older-aged Thai parents compared to parents in other settings where they are absent. These include a well developed public health system, reasonably widespread availability of government health insurance, an unusually successful effort to openly confront the epidemic and to educate the public about it, and low fertility among the generation of adults in the prime AIDS ages combined with high past fertility of their parents. Thailand also 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 the findings of the present study are likely to have considerable relevance for other developing countries with AIDS epidemics but also need to be understood in terms specific to the Thai context.



## Introduction

The global AIDS epidemic is typically associated with adults in their 20s, 30s and 40s and to a lesser extent with their young children who are left behind as AIDS orphans and who sometimes are infected themselves through perinatal transmission. Older adults are also very much impacted by the epidemic even though their situation has largely been ignored in the discourse about AIDS. Not only can older adults contract HIV themselves but, far more commonly, they experience multiple consequences as older generation relatives, particularly in their role as parents of younger adults who become ill and die from AIDS. Older persons also make significant contributions to the well-being of younger adults who suffer from AIDS by playing a major role in caregiving to their infected sons and daughters and by assuming the role of foster parents for their grandchildren who are left behind as AIDS orphans. In addition, older persons have considerable untapped potential for contributing to efforts to expand and improve the treatment of persons with AIDS. Very little research has been conducted so far on these issues, especially in developing world settings. One exception is the comprehensive study of AIDS and older persons that we and our colleagues are conducting in Thailand. This paper addresses the impact of the AIDS epidemic for older adults based on that research. The primary focus is on the consequences for and the contributions by older persons in their role as AIDS parents.

We start our discussion with a consideration of the numbers of infected and affected older persons in Thailand. Since parents of adults who become ill with and die from AIDS are the most common group of older persons who experience direct consequences of the epidemic, we provide a general framework for assessing potential effects on them. Next we provide a brief description of some relevant features of the Thai setting that are likely to condition the nature and magnitude of the impact of the epidemic on older-age AIDS parents. This is followed by a discussion of our data sources. The remainder of the paper presents some main findings of our research and concludes with an assessment of the relevance of the Thai findings for the older persons in other settings with serious AIDS epidemics.

## Older persons as infected and affected individuals

Older persons are impacted by the AIDS epidemic both as infected and affected individuals. AIDS has no age limit despite the fact that estimates of adult cases are typically presented in relation only to persons 15-49 (e.g. UNAIDS 2000). While the major risks behaviors that lead to HIV infection are less common among persons 50 and over, they are not absent. In Thailand, 5.4 percent of the more than 100,000 AIDS cases reported to the Ministry of Health through 1998 were to persons age 50 and older, a level fairly typical of the developing world as a whole (UNAIDS & WHO 2000; Knodel et al. forthcoming). In countries where HIV/AIDS has reached significant levels, the absolute numbers of infected older persons will be significant. In Thailand, for example, 5.4 percent of total cases translates into over 35,000 persons age 50 or older living with HIV/AIDS in 2000 assuming recent estimates of the overall caseload are correct.<sup>1</sup>

Far greater numbers of older people, however, are affected by AIDS through the infection of others, particularly through the illness and death of their adult children. Since most people who die of AIDS are in their 20s and 30s, their surviving parents are mostly in their 50s, 60s and 70s. And since one or both parents of adults with AIDS are usually alive, the numbers of these AIDS parents are very large. For example in Thailand, where recent estimates indicate that approximately 225,000 adult AIDS deaths had occurred by the start of 2000 (Thai Working Group on HIV/AIDS Projection 2001), the number of older

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<sup>1</sup> The recent projection derive age distributions of AIDS cases indirectly rather than from the national AIDS registry and thus differ from those presented here (Thai Working Group on HIV/AIDS Projection 2000).

persons who would have lost an adult son or daughter is likely to be well over 300,000.<sup>2</sup> To put this number in perspective, it is at least four fold the cumulative number of AIDS orphans in Thailand, estimated to be 75,000 (UNAIDS 2000). Yet while AIDS orphans receive much attention, almost no notice is given to the far larger number of older-age AIDS parents.

Another way to think about the demographic magnitude of the impact of AIDS epidemic on older persons is to consider the proportion of older Thais who will eventually lose an adult child before they themselves die. Even though the adult HIV prevalence rate in Thailand has peaked at about 2 percent, recent studies using micro-simulation indicate that 8 to 13 percent of Thais over age 50 as of 1995 are likely to experience the loss of at least one adult child to AIDS during their remaining lifetime.<sup>3</sup> Moreover, between one eighth to one third of those parents who suffer such a loss will lose more than one child (Wachter et al. 2002; Wachter et al. forthcoming). While AIDS is not the only source that leads to the death of adult children, it clearly increases the chances substantially. These same microsimulations indicate that that persons age 50 and over in 1995 have up to a 70 percent higher chance of suffering the loss of an adult child than if there were no AIDS epidemic.

As part of the general population, older persons are affected by the macro-level economic and societal impacts of the epidemic (Barnett & Whiteside 2000; Bloom & Lyons 1993; Godwin 1997). Although a discussion of these macro level impacts is beyond the scope of this paper, recognizing that such potential effects may exist is important (World Bank 1997). For example, if illness and death due to AIDS removes significant numbers of working age persons from the labor force, the old age dependency burden rises. In turn, this could hurt formal programs designed to assist or benefit older persons that depend on taxation and other forms of mandatory contributions from the current workforce. In addition, large numbers of persons with AIDS could compete for limited health services with older age persons who themselves generally have disproportionate health care needs. Also if the loss of workers due to AIDS lowers productivity and weakens the economy, the effects will spread to the general population including those in older ages. The loss of a younger family member to AIDS, however, particularly an adult son or daughter, can affect older persons through much more direct pathways than these macro-level impacts and will have far more immediate impacts on their well-being.

### **Pathways and Consequences of Family Level Impacts**

Table 1 provides a general framework describing the multiple pathways through which the illness and death of an adult child with AIDS can affect older-aged parents. It indicates the relation of each pathway to different dimensions of well being (emotional, economic, physical, and social) and the specific consequences for each of these dimensions that could result.<sup>4</sup> Except for grandparental fostering of AIDS orphans, potential family level impacts on older persons have only started to be explored. Although we frame our discussion in terms of AIDS parents, we note that other older generation relatives, such as

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<sup>2</sup> According to a 1994 nationally representative household survey, adults aged 20-44, the ages where most AIDS deaths are concentrated, have on average 1.5 living parents. If we assume adults who die of AIDS resemble the rest of the population in this respect, and we allow for the fact that some modest proportion of persons who die of AIDS are siblings with the same parents, the number of AIDS parents generated by an AIDS death in this age range would be modestly less than 1.5.

<sup>3</sup> The range largely represents differences between the various AIDS projections that are used as the basis for the microsimulations. The lower figure is based on the most recent set of government projections and reflect the presumed substantial declines in HIV incidence. The upper limit is based on projections made by the UN demographic division in connection with their 1998 assessment of the world population (Wachter et al. 2002; Wachter et al. forthcoming).

<sup>4</sup> This inventory builds upon earlier versions of a conceptual framework that guided our ongoing research in Thailand (Knodel, Saengtienchai, et al. 2001; VanLandingham et al. 2000).

grandparents or aunts or uncles (i.e. siblings of parents), could experience many of these same consequences.

*Caregiving.* Providing care to an ill adult child can affect all four dimensions of well-being of the older-age parent. As caregivers, parents can suffer considerable psychological pain witnessing the suffering and decline of their child. Caregiving demands enormous time and effort, especially at the terminal stage of AIDS. Parents may feel upset over anticipated or actual negative reactions from members of the community who associate the caregiving role with contamination by HIV. Adverse financial consequences can result when caregiving competes with time needed to earn a livelihood. Some caregiving tasks, such as lifting the ill adult child, may lead to physical strains. Also potential exposure to the opportunistic diseases associated with AIDS (especially TB) exists. Caregiving can divert time from social activities or lead to social shunning by others who have misgivings about being near the caregiver or the adult child with AIDS. Intra-familial relations can become strained if caregivers perceive inequities in the contribution of other family members.

*Coresidence.* Some adult children who become ill with AIDS lived with their parents prior to the onset of symptoms. Others return to the parental home because of illness. Not all coresident parents necessarily give care, although coresidence and caregiving are likely to be closely associated. Simply living with an adult child with AIDS has some of the same potential consequences as caregiving, including the psychological pain of daily witnessing the child's decline and concern over anticipated or actual negative community reaction. Coresidence can also put a parent at risk of exposure to opportunistic infections and curtail normal social life if community members avoid contact.

*Providing material support.* Parents may help with medical and living expenses associated with the illness or with the upkeep of the ill child's dependents. As a result, parents may go into debt, deplete their savings, or sell assets to cover these extra expenses. Such contributions can lead to anxiety among parents over their own economic security. A parent may need to take on extra work to cover the costs which, if physically taxing, could affect health.

*Arranging the funeral.* Funerals often involve significant costs for surviving parents and affect their economic well-being in the same ways as the expenses prior to the death. If community members avoid attending the funeral or act in offensive ways at the funeral (e.g. refusing food or avoiding the corpse), parents suffer socially and emotionally.

*Fostering grandchildren.* AIDS Parents may inherit responsibility for AIDS orphans with obvious financial implications. Emotional strains may result from negative community reaction towards the fostered grandchildren or worries about the costs of childcare. Physical strain and exhaustion can result from additional work required to cover these costs. Foster care may diminish social activities, lead friends and neighbors to avoid the family for fear that the grandchild is infected, or strain results in intra-familial conflicts over custody and responsibility for the grandchild.

*Child loss.* An adult child's death can devastate parents and lead to lasting grief (DeVries, Lana, et al. 1994; Sanders 1980). Current economic well-being may decline if the child who died contributed financially to parental support or assisted in household economic activities. Parents also lose any potential support that the deceased child might have provided in their old age. These situations could create anxiety and undermine their psychological state.

*Community reaction.* Negative reactions of others in the community towards the parents, either during the time of the child's illness or following the death, could cause psychological, economic and social distress. For example, a shopkeeper whose child dies of AIDS could lose business because customers fear contagion. If other family members have a similar fear, strained intra-familial relations may result.

Of the 7 pathways considered, all but the last two result from more or less volitional actions on the part of AIDS parents and thus the parents have some degree of control over them. Parents have little or no control, however, over the loss of the child and negative community reaction, the last two pathways, and thus less ability to manage the associated consequences for their well-being.

The extent to which these potential impacts actually occur remains largely for systematic empirical research to determine. They are likely to be context sensitive and thus to vary across different settings.

### **The Thai Setting**

Thailand is well suited for a study of the impact of AIDS on older persons in a developing country context. The AIDS epidemic there is of the longest duration in Asia (UNAIDS & WHO 1998; MAP 1998) and thus sufficient time has passed for many of the repercussions to be apparent. Moreover, the Thai Government has openly confronted the epidemic helping create an atmosphere conducive to objective research on the epidemic's causes and consequences (Phoolcharoen et al. 1998).

Thailand's AIDS epidemic began in the early 1980s and took off rapidly but only in the early 1990s were large numbers of persons becoming ill with and dying of AIDS. Recent Thai government estimates indicate that at the start of 2000, almost 700,000 Thais were living with HIV/AIDS and that nearly 300,000 had died of the disease (Thai Working Group on HIV/AIDS Projection 2001). Although incidence fell in response to organized efforts to combat the epidemic, these same estimates project that deaths will hover around 50,000 a year for the next decade (Phoolcharoen et al. 1998; UNAIDS 1998). While an adult prevalence level of 2 percent is modest compared to the worst hit African countries, it still places Thailand second only to Cambodia in Asia (UNAIDS 2000). Moreover, levels have been much higher in some sub-regions, especially in some 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 et al. 1998).

In common with 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 behavior that, at least until the AIDS epidemic became serious, had relatively little social stigma attached to it in Thailand (Knodel et al. 1996). Thai society is generally noted to be relatively tolerant of some forms of sexual behavior, including prostitution and homosexuality, that elsewhere often evoke strong negative views among significant proportions of the population (Jackson 1995; Peracca et al. 1998). More recently, infected men are increasingly spreading the virus to their wives and non-commercial partners (Chitwarakorn 1998). Almost half of new infections are attributable to women infected by a husband or other partner (Thai Working Group on HIV/AIDS Projection 2001).

During much of the period associated with the AIDS epidemic, the country was also experiencing a continuation of the rapid economic growth that began several decades ago. However, Thailand was also at the forefront of the Asian economic crisis that came to a head in mid-1997 and spread almost instantly to many others countries in the region (Gragnotati 2001; UNDP 1999). In assessing the economic consequences of the AIDS epidemic, whether on a societal, familial or individual level, it is important to keep in mind that other influences including the turbulent economic situation are also having an impact.

Thailand is currently a low fertility country. The average number of children couples have, as indicated by the total fertility rate, has fallen from approximately 6 to 2 between the late 1960s and the early 1990s and has remained low ever since. This has important bearing both for the number of adult children that an older age parent has and the number orphans who are left behind when an adult son or daughter dies of AIDS.

Intergenerational exchanges of support and services between parents and adult children are pervasive in Thailand as in much of the developing world, a situation which conditions the consequences of the loss of an adult child through AIDS or other illnesses (Knodel, Chayovan et al. 2000; World Bank 1994). Widespread norms supporting filial obligations to parents, including old age support in the form of remittances and coresidence underlie existing behavioral patterns (Knodel et al. 1995). At the same time, parents continue to feel an obligation to ensure their children do well. An important result of this familial system of intergenerational exchanges of support and services is that approximately half of adult children with a living parent aged 50 in the same local community as the parents and half of these coreside with parents. Moreover, the vast majority of adult children who lived away from the parental community maintain contact. Almost 90 percent return to visit parents during a year and two-thirds of these visit at least several times.<sup>5</sup>

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

### **Data Sources and Methods**

In this paper we draw primarily on three components of our research project: interviews with key informants about individual AIDS cases and their families; direct survey interviews with AIDS parents and a comparison group of older persons; and in-depth interviews with AIDS parents.<sup>6</sup> The first two permit quantitative analysis while the third is suited for qualitative analysis.

*Key informant study.* The key informant study involved interviews with persons knowledgeable about individuals who were living with or who died of AIDS in the community. Most were paid staff or volunteers associated with local health centers. Interviews were conducted during 1999 in 85 sites in rural and urban communities in 8 provinces (including at least one in each of the four major regions of Thailand) and in Bangkok. The study yields basic information on living arrangements and caregiving for over 1000 individual. In addition, for almost 300 cases whom the informants knew best, we asked for greater detail about the living arrangements and caregiving and inquired about limited aspects of the economic and social impacts on the family.<sup>7</sup>

*Direct interview survey.* The direct interview survey utilized a detailed structured questionnaire administered directly to AIDS parents and to a control group of parents of similar ages and backgrounds from the same survey sites. The AIDS parents all experienced the loss of at least one adult child to AIDS, usually within the prior three years. The control group had not experienced the recent death of an adult child. The survey took place during 2000 in three provinces, all of which were also included in the key informant study. Two provinces had relatively high prevalence (for Thailand), one in the upper north and

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<sup>5</sup> The statistics cited are from original tabulations based on the Survey of Welfare of Elderly in Thailand (Chayovan & Knodel 1997).

<sup>6</sup> For details of the methodology of the key informant study see (Knodel, Saengtienchai et al. 2000). For details of the methodology of the open-ended interviews see (Saengtienchai & Knodel 2001).

<sup>7</sup> For most purposes, our analysis is limited to 768 cases of adults who died locally, among whom 258 had supplemental information collected about them.

the other on the east coast; a third moderate prevalence province was in the lower north. In total, we conducted 394 interviews with AIDS parents and 376 interviews with control cases. However, in cases where both parents were alive and living together, certain items in the questionnaire were asked separately for each parent. Thus the interviews generated information for 649 AIDS parents (363 mothers and 286 fathers) and 621 control parents (345 mothers and 276 fathers).

Local health personnel served as intermediaries in identifying both the AIDS parents and control cases we interviewed. Prior to the survey, we visited each site and explained the purpose of the survey to the intermediaries and asked them to list all parents within the local area who had lost an adult child to AIDS. We eliminated a small number of cases from consideration whom the intermediary believed would be unwilling to be interviewed. After setting a date for the interview team to conduct the survey at the site, we asked the intermediary contact those remaining on the list and request permission for an interview. We also asked the intermediary to prepare a list of persons of comparable ages and economic backgrounds as the AIDS parents but who had not experienced any recent death among their children. In order to make the actual interviews with AIDS parents less sensitive, during the interview we did not refer to AIDS as the cause of their child's death unless the respondent volunteered the information first. In most sites, the large majority of AIDS parents who were initially identified agreed to be interviewed and in two-thirds of these cases, the respondent admitted during the interview that their deceased son or daughter had AIDS.<sup>8</sup>

*Open-ended interviews.* We also draw on a qualitative analysis of transcripts of 19 open-ended interviews conducted during 1999 with AIDS parents to supplement the quantitative analysis. The cases selected for study were drawn from Bangkok and three other provinces (all three were also covered by the key informant study and two were included in the direct interview survey). The open-ended interviews cover many of the same issues as the direct interview survey. Their open-ended nature encouraged interviewees to elaborate on these issues and the circumstances affecting them. The open-ended interviews were recorded and fully transcribed.

*Comparison of sources.* There are serious methodological challenges to obtaining representative information about parents of persons with AIDS. Any practical approach is likely to be prone to some type of bias. The three data sources described above are no exception. The open-ended interviews are based on a small number of cases and thus are limited to serving mainly an illustrative role. Moreover, while both the key informant study and the direct interview survey provide sufficient cases for quantitative analysis, neither is based on a probability sample and thus the results can not be statistically generalized in any rigorous fashion. Nevertheless, we hope that our multi-method approach will produce a combination of results that can reasonably represent the situation.

The key informant study and the direct interview survey have complimentary strengths and weaknesses. In the key informant study, all information on the person with AIDS and their parents were provided by a proxy. In the direct interview survey, the respondents provided information about themselves and served as a proxy for information about their own deceased son or daughter. Thus of the two sources, the direct interview survey provides more detailed and almost certainly more accurate information for an individual case. As discussed below, however, the key informant study is likely to be more broadly representative of AIDS parents in general. Both sources address some of the same issues thus permitting comparisons of results. The direct interview survey also permits a number of comparisons to be made between AIDS parents and control group parents from which the impact of losing an adult child to AIDS can be inferred.

In the key informant study, we start by asking local informants to identify adults in the local area who were currently symptomatic or who had died of AIDS and solicited information for all cases, regardless

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<sup>8</sup> It is not possible to calculate an exact response rate because a potential case could be eliminated at several stages of the selection process and exact records were not kept to tally the appropriate numbers at each stage.

of whether the parents lived locally, lived elsewhere, or were no longer alive.<sup>9</sup> In the direct interview survey, we asked the intermediaries to identify parents who lived in the local area and who had lost an adult child to AIDS either locally or elsewhere. The intermediaries were generally able to identify parents whose child died locally since local AIDS deaths are typically known, especially to health personnel. However, they found it difficult to identify those parents whose child died elsewhere (unless the funeral was held locally) since the child's death would not necessarily be known to them. Hence the direct interview survey is skewed toward cases in which the parents and the deceased son or daughter either lived in the same community since before the child became ill or in which the deceased adult child became ill elsewhere but returned to the parental community before dying. The under-representation of parents whose child died away from their locality is important because such parents are less likely to be involved with caregiving and are probably less vulnerable to some of the potentially adverse economic and social impacts. Moreover, they may well differ in other aspects of their relations with the child compared to parents whose child was in the same community at the terminal stage of illness.<sup>10</sup> The direct interview survey is also limited to parents willing to be interviewed while the inclusion of a case in the key informant study did not depend on this. Again, since willingness to be interviewed is potentially related to some of the outcomes we wish to study, the key informant data are more broadly based.

Table 2 compares the expected age distribution of AIDS parents in Thailand with the distributions found in the key informant study and direct interview survey. The expected distribution is derived from two sources: 1) the age distribution of adult AIDS cases as reported in the national AIDS registry for 1997-99 and 2) information from a 1994 nationally representative household sample that provided information on the age of each household member and the survival status and age of his or her mother and father. If we assume that persons with AIDS resemble the general population at equivalent ages with respect to the survival status and ages of their parents, the expected age distributions of AIDS parents (at time their adult child is diagnosed with AIDS) can be easily generated.<sup>11</sup> As table 2 shows, the age distribution of AIDS parents as reported both in the key informant study and the direct interview survey are very similar to the expected distribution. All three distributions indicate that the vast majority of AIDS parents are at least age 50 and approximately half are 60 or older. Thus at least in terms of age, our approaches appear to be covering fairly typical cases.<sup>12</sup>

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<sup>9</sup> We also asked minimal information about cases who became symptomatic in the area but left before dying and about cases who were from the area but died elsewhere. However, we do not include these cases in any of our analyses on several grounds. Key informants often had very limited knowledge about such cases and generally were not confident in their ability to identify them. In addition, from a sampling perspective, such cases would in principle have two chances of entering the sample (as a local case where illness or death occurs and as a case in the community of origin who went or died elsewhere).

<sup>10</sup> Based on the key informant study, we estimate that a parent was a main caregiver in 59 percent of the cases in which there was at least one living parent compared to 71 percent of the cases covered by the direct interview survey. The latter results are clearly biased upwards in this respect. However, there is less reason to expect that direct interview survey provides biased information about caregiving among those parents who were involved in providing care to their ill adult child.

<sup>11</sup> More specifically, the expected age distribution of parents of adults with AIDS was calculated from a matrix which showed the percentage age distribution of living mothers and living fathers for adults in each age group in the general population (as provided in the 1994 Survey of Elderly in Thailand (National Statistical Office no date). By weighting that matrix by the proportionate age distribution of adult AIDS cases in the national registry, we obtain the expected age distributions of living mothers and fathers assuming that the AIDS cases in each age group had living parents of similar ages as the equivalent age groups of adults in the general population. By combining mothers and fathers, we obtain the expected age distribution of parents.

<sup>12</sup> It is also somewhat reassuring that the AIDS cases reported by the key informants and by AIDS parents themselves fairly closely resemble the national caseload of adult cases as represented by the national AIDS registry with respect to age, sex and marital status distributions (Knodel & VanLandingham 2001; Knodel, Saengtienchai, et al. 2000).

For persons with AIDS, living and caregiving arrangements often change during the course of the illness. Many initially care for themselves but at later stages require assistance. Thus some who live away from their place of origin at the onset of symptoms return when they can no longer earn a living or when they need care assistance. Since substantial return migration occurs at advanced stages of the illness (as shown below), the extent of parental involvement in caregiving and other forms of support during illness is fully evident only for cases who have already died of AIDS. Moreover, the full extent of some impacts on parents of an adult with AIDS are manifest only after the death of the child. Thus, in the case of the key informant study in which we collected data on currently symptomatic cases as well as those who died, we limit analysis to the latter. None of our three data sources, however, captures truly long range impacts of the epidemic since the deaths of children involved are too recent for such impacts to have fully emerged.

### Caregiving and Living Arrangements

*Overview.* Older Thais are extensively involved with their infected adult children though both living and caregiving arrangements. Figure 1 presents results from the key informant study which, for the reasons explained above, we believe are representative of a reasonably broad range of AIDS parents. The majority of adults who died of AIDS (59 percent) co-resided with a parent at the terminal stage of their illness and fully two-thirds either co-resided with or lived next to a parent. Moreover, parents assisted in personal caregiving for almost two-thirds of adults who died of AIDS and were main caregivers for half. If consideration is limited to adults who had at least one living parent, the results are even more striking. For example, coresidence at the terminal stage rises to almost 70 percent and for almost 60 percent a parent was a main caregiver.<sup>13</sup>

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

There is a clear gender dimension to personal caregiving as table 3 shows. Mothers are more likely than fathers to provide personal care and are particularly more likely to be a main caregiver. The gender differential reflects in part the greater likelihood that an adult person with AIDS has a surviving mother than a surviving father as revealed by comparing results from the direct interview survey based on all cases and those conditioned on having both parents alive.<sup>15</sup> Nevertheless, even for cases in which both

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

<sup>14</sup> Such direct conditioning can not be done with the key informant study data because allowance need to be made for cases in which the living status of the parents is unknown.

<sup>15</sup> Based on the age distribution of persons who died of AIDS as stated in the latest Thai national projections and information of the survival status and age of mothers and fathers of adults of different ages in the general population from a 1994 national household survey, we estimate that during the period 1996 - 2000 there is about a 25 percent greater likelihood that the mother than the father of an adult AIDS case to be still living.

parents were alive, the mother was 2.8 times more likely than the father to be a main caregiver. Instrumental help shows far less pronounced gender differentials. When both parents are alive, fathers and mothers are about equally likely to provide some instrumental help and mothers are only 20 percent more likely than fathers to be the main provider of instrumental help.

The in-depth interviews we conducted with AIDS parents confirm the quantitative results in table 3. In several cases it was clear that both parents were heavily involved in caregiving and in several other cases the father played at least a moderately supportive role. In some families the lesser involvement of a father in personal caregiving was related to his position as the main income earner. In such situations, daily caregiving would entail greater opportunity costs for the father than for the mother. Men, typically the father or a brother, were commonly cited for providing transportation when the person with AIDS needed to go to the hospital and helping when greater physical strength was needed (e.g. when the ill person needed to be lifted or carried). Thus, while men may play a minor role in routine care, they can be of critical importance when special tasks are required.

*Routes to parental caregiving.* In understanding the high prevalence of parental terminal stage caregiving to adults with AIDS in Thailand, it is useful to recognize that there are two basic routes that lead to the situation. In some cases the son or daughter is already living with or near the parents even before becoming ill; in others, the adult child lives elsewhere when symptoms first appear but returns to the parental community after becoming ill. Both routes are substantial. As noted in the discussion of the Thai setting, about half of adult children of older-age parents live with or nearby them even under normal circumstances. Such residential proximity obviously promotes parental involvement during times when a son or daughter falls ill. At the same time, substantial return migration of seriously ill adult children, especially in cases of a fatal and incurable disease such as AIDS, is frequent in the Thai context.

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

Both the key informant study and the direct interview survey indicate that a substantial share of adult children who were cared for by parents at the terminal stage had returned home from elsewhere. As figure 2 shows, the percentage indicated by the key informant study is somewhat higher than by the direct interview survey. Taken together they suggest that between a third to two fifths of adult children with AIDS who received care from their parents at the terminal stage of illness had returned home from elsewhere. Both sources indicate that the percent of return migrants is higher among daughters than sons who received care. This could reflect a lesser tendency for husbands than wives to be caregivers when a spouse falls ill as well as a tendency for husbands to predecease wives in couples in which both are infected.<sup>16</sup> The nature of our calculations, however, precludes any definitive interpretation of gender

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

differences in the tendency to return for parental care. In order to determine such differences, we would need to relate the number of return migrants to the ‘population at risk’ of return, i.e. the total number of adult children with parents in the locality who became ill when living away, regardless of whether or not they returned. Unfortunately, we lack sufficient information on the numbers who do not return. Thus the higher proportion of return migrants among daughters compared to sons in theory could simply reflect that a higher proportion of daughters than sons are living away from their parental home at the times they become symptomatic. We have no way of knowing if this is the case from our data.<sup>17</sup>

The direct interview survey makes clear that in many cases, adult children with AIDS who return to their parents do so at an advanced stage of the illness. Figure 3 shows the cumulative percentage dying within specified periods among adult children who were cared for by a parent at the terminal stage of illness. Almost one fifth die within less than a month and almost half die within three months. The key informant study agrees well with this indicating that 47 percent of adult children who died of AIDS and lived with and were cared for by their parents died within ‘a few’ months.

*Caregiving duration.* Regardless of the route through which parental caregiving arises, its duration usually is a matter of months. Table 4 shows parental caregiving duration both for those adult children who were living in the parental locality before the onset of symptoms as well as those who returned after becoming ill. On average the duration of caregiving is modestly shorter for those who returned from elsewhere. However for approximately a third of both groups, caregiving lasted less than a month and even for those who were in same community from the start, less than a fifth were given care for 6 months or more. The moderate duration of parental caregiving probably reflects a combination of short survival times after the onset of AIDS in Thailand and attempts on the part of many adult children to take care of themselves as long as they are able. Although the duration of parental caregiving may be modest, it occurs during the most disabling stage of the illness and is thus likely to be intensive as well as particularly emotionally and physically draining for both parent and child.

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

In the direct interview survey, if either parent gave any personal care or instrumental help to their deceased child, they were asked what specifically they had done. If a specific task was not mentioned spontaneously, the respondent was probed by the interviewer about it. When both parents were involved, the question referred to their combined efforts and did not distinguish between tasks done by each. Thus it is not possible to examine directly gender differences in parental assistance. However it is possible to distinguish among cases in which only a mother, only a father or both parents assisted. The results are shown in Table 5 in the order of the frequency with which they were mentioned. In a majority of cases in which only the mother or only the father provided assistance, the other parent was deceased (63 and 58 percent respectively - results not shown).

For the full set of parental caregivers, the most common task was watching over the ill adult child followed by food preparation. In a majority of cases, a parent had to help with very basic needs such as feeding, using the toilet, bathing and dressing. Several tasks involving instrumental help were also quite common, especially shopping for food and providing transportation for the ill son or daughter. Other instrumental help such as applying for welfare and managing financial affairs were relatively uncommon.

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

The results make clear that parents are commonly involved with the interactions between the ill adult child and the health system, including transporting the son or daughter to health facilities, helping administer medicines and consulting with health care personnel.

Clear differences are apparent in the frequency with which most tasks were mentioned according to which parent provided assistance. For almost all tasks, the percentage mentioning doing the task is higher when both parents assisted the ill child compared to when only one parent was involved. However, the percentage mentioning specific tasks was typically only modestly lower when only the mother was involved rather than both parents. In contrast, when only the father provided assistance, many tasks were substantially less likely to be done.<sup>18</sup>

Our in-depth interviews with AIDS parents confirms the wide variety of tasks involved in caregiving to an adult child with AIDS. One very important task, not asked about in the direct interview survey was providing emotional support to the ill son or daughter. Parents in the in-depth interviews reported a wide range of reactions of their children to their situation of having AIDS. Several mentioned the infected child tried to keep up a brave face so as not to worry the parents. Some felt their child was able to accept his or her fate rather stoically. Other adult children were very depressed, distraught or even suicidal. Reactions also varied over the period of illness. Trying to relieve despair and boost the morale of a person facing a fatal disease is clearly an important but particularly challenging and trying part of caregiving, especially when the illness is severely debilitating and sometimes stigmatized as with AIDS. The task is all the more difficult when the person being cared for is one's own adult child.

### **Health impacts on parents**

The fact that many AIDS parents are in older ages makes them particularly vulnerable to physical strains associated with caregiving. In the direct interview survey, respondents were asked if they or their spouse experienced health problems during caregiving and were probed about a set of specific conditions. As table 6 shows, substantial proportions of parental caregivers reported each of the problems asked about. Almost three-fourths of parental caregivers reported experiencing nervousness or anxiety and over two-thirds reported insomnia, both suggesting that caregiving is accompanied by considerable mental and emotional stress. Over half of the parental caregivers also reported fatigue. Strained muscles as well as headaches and stomachaches were also fairly common being reported for sizeable minorities of caregiving parents.

The results in table 6 also reveal that overall among parental caregivers, mothers were more likely than fathers to report each of the health problems listed. To some extent however, this results from the greater involvement of mothers than fathers in personal caregiving, particularly as main personal caregivers. For both mothers and fathers, being a main personal caregiver, increased the chance of experiencing each of the health problems, usually to a substantial extent. Differences in the percent experiencing each health problem are modest or virtually absent between mothers and fathers who were main personal caregivers. However, since mothers are much more likely to take on a main personal caregiving role, they also tend to be more likely overall to experience the health problems listed.

Comparisons between older aged parents who did not lose an adult child to AIDS (the control cases in the direct interview survey) with those who did suggests that for some AIDS parents, the experience of losing a child had a longer term detrimental impact on their health. Both groups were asked to compare their current health status with the situation three years ago. For most AIDS parents this would be before their adult child died (although in some cases the child would have been ill with AIDS at the time). Results are

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<sup>18</sup> Some caution is called for in interpreting the differences between cases in which only the mother and only the father provided assistance given the small number of cases of the latter. The differences are statistically significant at the .05 level (based on a two-tailed t-test) only for the following: preparing food; shopping for food; cleaning, laundry, and doing dishes; consulting with health care providers; bathing; and dressing.

shown in table 7. Compared to control parents, AIDS parents were less likely to report that their health now was much better or somewhat better than three years ago and more likely to report that their health was worse or much worse. This holds both for mothers and fathers. The differences between the AIDS parents and the controls, however, is rather modest. Both groups were considerably more likely to report that their health worsened rather than improved perhaps reflecting the relatively advanced ages of both groups.

Psychological and emotional strain were commonly reported as a concomitant of parental caregiving in our open-ended interviews. Some of the circumstances of caregiving that gave rise to emotional strain for parents included facing the worsening condition and inevitability of death of their child; adjusting their lives to accommodate the care-giving role; and striving to do their as much as possible to alleviate the child's suffering. As the stages of illness progress, parents are forced to witness the deterioration of the ill child, which often is particularly severe towards the end. It was always emotionally stressful for parents to go through the terminal stage, particularly when parents saw the ill child suffer in pain or had difficulty moving his/her deteriorated body and knowing it would end in death. In addition, parents often hesitate to share their feelings and seek emotional support from their normal social network, in part because of fear of negative reactions from neighbors and acquaintances in the community.

The open-ended interviews also revealed that the experience of losing an adult son or daughter to AIDS is an emotionally wrenching experience which in some cases leads to lasting grief and sorrow. Responses to questions about happiness in the direct interview survey appear to reflect this. Both AIDS parents and the control group of parents who did not experience any recent death of a child were asked how happy they were at present and if they were more or less happy now compared to three years ago. As the results shown in table 8 reveal, AIDS parents compared to the control group of parents are more likely to say they are unhappy at present and also more likely to indicate that their level of happiness has declined over the last three years.<sup>19</sup>

### **Fostering grandchildren**

The one pathway through which the AIDS affects older persons that has attracted attention in discussions of the epidemic is their role in fostering grandchildren who become orphaned because of AIDS (see e.g. (UNAIDS 1999; UNICEF 2000). Indeed, taking on the responsibility for raising the dependent children left behind by an adult son or daughter's death potentially has substantial long-term implications for the grandparents.

Table 9 indicates the percentage of AIDS parents involved in the care and living arrangements of AIDS orphans based on the key informant study and the direct interview survey.<sup>20</sup> In considering the potential impact of AIDS orphans on AIDS parents in general, it is important to recognize that fostering a grandchild can only occur if the deceased adult son or daughter had surviving dependent children. In the case of Thailand, a substantial number of adults dying of AIDS have no surviving children and thus there is no AIDS orphan for the grandparents to foster. Our results suggest that probably for no more than half of all AIDS parents did the deceased adult child have a surviving dependent child. Two results are shown for the key informant study. The first is based on parents of all cases for whom it was known that there was a surviving parent; the second is based on the parents of the subset of persons who died of AIDS for whom the key informant provided supplemental information. The former is based on a substantially greater number of cases and probably is more representative of AIDS parents because of the stigma sometimes associated with the disease and the fear of negative reactions from neighbors and

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<sup>19</sup> Both sets of results are statistically significant at the .001 level.

<sup>20</sup> For the purpose of this discussion, we refer to any child who loses a parent as an AIDS orphan regardless of whether or not the other parent is still alive.

acquaintances in the community. It also agrees closely with the result from the direct interview survey. The results based on the subset of cases with supplemental information is provided, however, because only for this subset do we have information on the role of AIDS parents in caring for AIDS orphans and thus they serve as the base for the other findings in the table from the key informant study.

The main reason why many AIDS parents do not have an orphaned grandchild is that a substantial minority of adult children who die of AIDS in Thailand have never married (and non-marital childbearing is low). For example, according to both the key informant study and the direct interview survey about 30 percent of the adult with AIDS were never married and had no children. In addition, a substantial minority of the married AIDS cases were childless at the time of death either because they had not yet had children or because their children died. Moreover, according to the direct interview survey, most of the deceased adult children (71 percent) who had a child had only one, reflecting the low fertility levels that have prevailed in Thailand recently. It is also important to recognize that even if both a husband and wife die of AIDS and leave orphaned children behind, there still are usually two sets of grandparents (both the maternal and paternal) who potentially could foster the grandchildren but typically only one set will actually take on the responsibility of doing so.

In both the key informant study and the direct interview survey, information was solicited on whether or not the AIDS parents ever cared for orphaned grandchildren. Given that for half or more of AIDS parents, their adult child's death did not result in any orphaned grandchildren, when all AIDS parents are considered, only a minority ever cared for an AIDS orphan. However, if consideration is limited to those AIDS parents for whom there was at least one surviving orphaned grandchild, then the proportion who ever cared for the grandchild is much higher, with the key informant study indicating a third and the direct interview survey two-thirds did so.

At least part of the reason why the two quantitative sources provide such different estimates of grandparental involvement in AIDS orphan care is suggested by our qualitative analysis of open-ended interviews with AIDS parents. That analysis strongly suggests that the circumstances that lead to grandparental fostering of AIDS orphans are closely linked with the living and caregiving arrangements of the adult children with AIDS at the terminal stage of illness (Saengtienchai & Knodel 2001). AIDS parents who act as main caregivers to their ill adult child or who co-resided with or lived nearby (including cases in which the adult child returned to the parental home during the illness) are likely to inherit the responsibility for the ill child's offspring, particularly if the ill child's spouse is dead, HIV infected, or not in a good position to take care of children. As noted above, the selection of cases in the direct interview survey is almost certainly biased towards AIDS parents who lived with or nearby their deceased son or daughter and provided care for them, i.e. those who are particularly prone to take responsibility for fostering orphaned grandchildren. Thus the direct interview survey results likely overstate grandparental involvement in care of AIDS orphans. It is also possible, however, that the key informant study underestimates grandparental involvement in care of AIDS orphans. This would occur if the informants only reported involvement for the grandparents who took the main responsibility for the AIDS orphan and neglected to mention (or did not know about) situations in which grandparents assisted but did not have sole or primary responsibility. In contrast, respondents in the direct interview survey when asked if they provided any care to orphans would know about and be likely to report such care regardless of whether or not they took primary responsibility.

Additional information on the living arrangements of the orphaned children is available from the direct interview survey and is consistent with substantial involvement of AIDS parents with the care of their orphaned grandchildren. Among AIDS parents who had an orphaned grandchild, almost sixty percent had ever had the AIDS orphan living with them and almost half were currently living with an AIDS orphan at the time of the survey. Again, caution is needed in interpreting these figures given the likely bias in the direct interview survey towards cases with grandparental involvement. Nevertheless, despite this bias, when all AIDS parents are considered, only a fourth report ever living with an AIDS orphan and only a fifth report currently doing so.

Although it seems clear that most AIDS parents in Thailand are not involved in fostering AIDS orphans, at least several caveats are called for. First, the estimates provided by both our sources represent the situation as of the time of data collection and do not take into account the likelihood that a number of AIDS parents who are not currently fostering their grandchildren will do so in the future. According to the key informant study, approximately half of the children of persons who died of AIDS were being cared for by a surviving spouse (Knodel, Saengtienchai et al. 2001). Some significant proportion of surviving spouses of persons who died of AIDS, however, are themselves infected by HIV and are likely to die before the dependent child grows up. In many such cases, grandparents are likely to take over responsibility for the orphans. Second, the results reported in table 9 refer to the situation of AIDS parents associated with the loss one deceased child per parent. Some of these AIDS parents have lost or will in the future lose more than one adult child to AIDS and thus be at additional risk of having an orphaned grandchild. Hence, the results in table 9 somewhat understate the percent of AIDS parents for whom a grandchild will be orphaned by AIDS. Finally, for those who are involved in fostering grandchildren, the impact on their lives is likely to be lasting and substantial. Just as they are reaching an age when they could be expected to receive substantial assistance from their adult children in the form of services or material support, they must takeover the responsibility of raising another young child.

### **Economic impacts**

Illness and death of an adult child from AIDS can have numerous economic repercussions for older-age parents. The most immediate effects are likely to stem from expenses the parents incur associated with treatment, caregiving and funeral costs. If caregiving responsibilities divert substantial time away from income generating activities, opportunity costs could increase the difficulty of meeting these expenses. The parents may need to sell property or major possessions or go into debt in order to cover them, with potential consequences lasting for some time after the death. In addition if the deceased son or daughter had been contributing to the parents' household income, and especially if the adult child was a main contributor, the loss of income could lead to a sustained long term reduction in economic well-being.

The fullest accounting of potential economic impacts on AIDS parents is available from the direct interview survey. Table 10 summarizes several key indicators and how they are associated with the caregiving and economic status of the AIDS parents.<sup>21</sup> Since the direct interview survey is skewed towards parents who were involved in caregiving and who lived with or near the deceased child during the terminal stage of AIDS, the percentage of AIDS cases for whom a parent was a main caregiver is quite high (over 70 percent compared to the 50 percent indicated by the key informant study). As table 10 shows, this tendency varies little across the three economic strata. Thus the results from the direct interview survey are likely to overstate the economic impact on AIDS parents generally. However, there is less reason to expect that results for those who were main caregivers are not typical of this large segment among the general population of AIDS parents. Also there is no evidence that the selectivity of the direct interview survey differs according to economic status.

According to the direct interview survey, parents played a main role in paying for treatment for their ill adult child in slightly over 60 percent of the cases. This compares with between 37 to 52 percent as indicated by the key informant study (the lower figure excludes cases in which parents shared main responsibility with others - results not shown, (see Knodel, Saengtienchai, et al. 2001).<sup>22</sup> The direct interview survey also clearly indicates that serving as a main caregiver sharply increases the chances of

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<sup>21</sup> The measure of economic status is based on a combination of self-assessed status and the interviewers impression of the respondent's house.

<sup>22</sup> In this section, all comparisons with the key informant study are based on the subset of cases for which the informant provided supplemental information and refer to cases in which the adult child had already died and had at least one parent alive at the time of illness.

being a main contributor to expenses during illness. Better economic status also increases the chances the parents will be main contributors to expenses during the illness.

In almost half of the cases, one or both parents had to either stop or reduce their economic activities. Curtailment of economic activity was over twice as likely for cases in which a parent was a main caregiver than in those in which a was not. Also the lower the economic status of the parents the higher the percentage reducing their work. These estimates are considerably higher than ones from the key informant study that indicated reduced economic activities by a parent in about a fifth 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).

Funerals usually are major social events in Thailand. They typically last at least several days and involve treating guests to refreshments or meals and can be quite expensive. The burden of paying for a funeral in Thailand is commonly mitigated by the customary practice of making monetary contributions towards expenses by those attending. Also many families belong to local funeral societies as a form of insurance. In return for making regular payments, a member receives a lump sum benefit when there is a death in the family. Open-ended interviews with AIDS parents suggest some funerals of person dying of AIDS are of shorten duration and have more limited attendance than usual. They also revealed that in several cases, the cost of the funeral was more than covered by some combination of neighbors contributions, funeral society benefits, and welfare payments(Saengtienchai & Knodel 2001). Nevertheless, it is very common for parents to have had net costs associated with the funeral of their deceased adult child. As table 10 shows, in almost 70 percent of the cases covered by the direct interview survey, the parents incurred net funeral costs and in well over half had substantial net costs. Both situations were more common for cases in which a parent provided net 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.

Supporting orphaned grandchildren can also be a significant expense for AIDS parents especially since such support can last for years. According to the direct interview survey, in almost a third of the cases the AIDS parents were paying expenses for an AIDS orphans. This varies little by caregiving or economic status.

In almost 40 percent of cases, the parents had to borrow money and in about a fifth of the cases the parents sold property or possessions to pay for expenses associated with the illness and death of the deceased adult child. Both were more likely to occur when a parent was a main caregiver. Also the percentages are inversely associated with economic status with poorer parents being more likely than better off ones to borrow or to sell something to meet expenses.

From a longer term perspective, the most serious economic impact for some AIDS parents is the loss of the future support the deceased would have provided. This is especially the case when the son or daughter who died had been a main contributor to household income. The direct interview survey results indicate that in over 70 percent of cases, the deceased child provided some material assistance to the parents during the year prior to death and in almost a third had been the main income provider. 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 to depend on adult children for support among poorer older persons than richer ones.

Given that most AIDS parents at the time of our research were in their 50s and 60s and thus had their children when fertility levels were relatively high or moderate, the vast majority who lose an adult child to AIDS still have other adult children to depend on and who potentially could compensate in terms of the lost support. For example, over half of the deceased children had 3 or more siblings still surviving at the time of our survey and in less than 2 percent of the cases did their death leave their parents childless.

Nevertheless there is no guarantee that the contributions of other adult child will fully make up for the lost support, especially of a sibling who was the main earner for the parents. Some indication that other adult children do not fully compensate is provided by a comparison between the AIDS parents and the control group of older age parents who did not experience any recent death of an adult child. When asked if the amount of support received from children had changed over the past three years, considerably more AIDS parents than those in the control group said that support had declined (42 versus 26 percent).

In the direct interview survey, only a third (33.8 percent) of the overall sample of AIDS parents said the expenses they incurred in connection with caregiving and the funeral were a serious burden to them (results not shown). One reason why the proportion who felt the expense were a serious burden was not higher is that in 60 percent of the cases, the deceased adult child was covered by basic health insurance, mainly through some government plan. Although the insurance did not cover expensive antiretroviral treatments, at the time of the survey such drugs were not widely available or even known to either persons ill with AIDS or their parents (Im-em, et al. 2001). In about half of the cases who had insurance, or about a third of all cases, the parent said that the insurance helped very much in covering the medical expenses.

Another way AIDS parents can moderate the economic impact of losing an adult child to AIDS, is to adjust their spending to their circumstances. Our open-ended interviews with AIDS parents indicated that many, especially those who are of moderate or better off means, were willing to go to almost any length to try to save their child. At the same time, without real availability of effective (and expensive) anti-retroviral treatments, their options were limited. Some parents, while eager to help their ill son or daughter, also worried about the long run implications of spending more than they could realistically afford. Moreover, for parents of little means, once they exhausted their own funds, they had few resources they could mobilize to get additional funds to spend on treatment or related expenses. A number of the results in table 10, suggest that poorer AIDS parents were less likely pay for some expenses. Yet poorer parents appear to be particularly vulnerable to adverse economic consequences from the loss of an adult child to AIDS. For example, compared to other AIDS parents, table 10 indicates that those of poorer economic status were more likely to curtail economic activities, to go into debt, to sell property or possessions, to lose a child who was contributing to the household income, and to lose a child who was the main income earner.

Figure 4 compares AIDS parents in the three economic status groups in terms of their mean combined care and net funeral costs and the percent who reported that these costs were a serious burden based on the direct interview survey. It clearly illustrates that both spending and adverse economic impact are related to economic status although in opposite directions. A strong inverse association exists between economic status and the amount spent as a result of the illness and death of the adult child. In contrast a strong positive association is apparent between economic status and the percent who reported that the costs were a serious burden for them. A very similar pattern is evident from the key informant study results. According to the informants reports, the percentage of cases for which expenses were substantial was inversely related to the parent's economic status prior to the adult child's illness. At the same time, the percent of parents whose economic situation was judged to have noticeably worsened was also clearly inversely related to their economic status (results not shown - see Knodel, Saengtienchai, et al. 2001). Apparently, even if expenses were not large in absolute amounts for poor parents, they were still more likely be severely taxing relative to their resources.

### **Social impact**

AIDS is a stigmatized disease throughout much of the world although the nature, degree, and consequences of stigma are likely to vary considerably across settings and over time (Leary & Schreindorfer 1998). Stigma may extend beyond the infected persons to those closely associated with them, especially those who are providing personal care (Brabant 1994; Powell-Cope & Brown 1992). Some main manifestations include negative attitudes towards and disassociation with those who are stigmatized and thus can undermine their social activities and contacts. Stigma associated with AIDS may

also prevent the infected person and their family caregivers from asking others for assistance or seeking services from health or social service providers (Ory et al. 1998). Our research suggests that in Thailand by the late 1990s, most community reaction experienced by AIDS parents was relatively sympathetic to their situation although negative experiences continue to affect some.

In the key informant study, we asked informants about their general impression of the local community reaction to families with a member who has AIDS and whether the reaction has changed over time. Virtually everywhere, the informants said that community reaction had improved over the course of the epidemic. For most (71 percent) of the sites, the key informants said persons in the community did not act unusual towards families in which a member has AIDS and in only 12 percent of sites was the predominant reaction described as avoidance and/or criticism. We also asked for case-specific information for the subset of cases the informant knew best. Negative community reaction to the family during the time of illness was reported for 28 percent of cases. Following the death of the person with AIDS, less than 1 in 10 families are reported to have experienced negative community reaction.

It is quite possible that key informants would not know much about the more intimate social relations and personal experiences of the families of AIDS afflicted persons and that a much less optimistic picture would emerge when the families are asked themselves. Results from the direct interview survey, however, are quite consistent with those from the key informant study. Table 11 summarizes the reaction of neighbors and other community members to the respondent and his or her spouse during the time when the adult child was ill and after the child died as reported by AIDS parents themselves. Fully two thirds of respondents reported that they only experienced positive reactions such as expressions of sympathy or offers of help, during the time their adult child was ill with AIDS and three-fourths said the reactions following the child's death were only positive. This differs little between cases in which a parent served as a main caregiver and those in which a parent was less involved in the care of the sick child. Moreover among those who reported experiences with negative reaction, most indicated that their experience was of a mixed nature and for only a relatively small minority was the reaction solely or mainly negative.

When asked more specifically about positive reactions during the time of illness, over 90 percent of respondents said that other community members visited and almost two thirds said some brought food (results not shown). More than a third reported that friends and neighbors helped in looking after their ill adult child and helped with providing transportation. In contrast, only a fourth of respondents reported that others gossiped about them, only a fifth said some in the community avoided visiting during the period of the illness and only one in seven said that some avoided talking with them. When asked about specific reactions following the death of their adult child, 95 percent said community members helped with the funeral and 90 percent reported social visits. Also just over 90 percent said that the number attending the funeral was large or normal. At the same time, only one in six reported gossip about their situation following their child's death and less than 10 percent reported that some community members refused to attend the funeral, refused to eat at the funeral, or avoided social contact.

It is possible our results somewhat understate negative reaction as a few AIDS parents mentioned that others in the community did not know of their child's illness and a few others indicated that there neighbors did not react one way or the other. Both of these situations may reflect efforts on the parents part to prevent knowledge of their child's illness from spreading because they anticipated negative reactions. Also AIDS parents who had particularly bad experiences may have been unwilling to be interviewed. Still the overall picture is one in which most parents of persons with AIDS find sympathy and support from their friends and neighbors and do not suffer severe social consequences as a result of losing a child to AIDS.

The qualitative results of our open-ended interviews with AIDS parents are consistent with the quantitative results from the key informant study and the direct interview survey. Positive experiences were mentioned somewhat more frequently than negative ones and it was not unusual to experience both types. The most common positive reactions mentioned by those interviewed included visits by others and

continuing shows of friendship; the most common negative reactions included gossiping, avoiding contact, acting repelled by the appearance of the person with AIDS, and boycotting food products sold by the family. Most of the negative reactions reported in the open-ended interview whether directed at the ill person only or extended to other members of the family, appeared to be out of fear of possible contagion. Rarely did negative reactions carry a moral overtone. The relative tolerance of the risk behaviors underlying AIDS in Thailand note above, and especially of commercial sex patronage, means likely helps account for the general lack of moral disapproval that we found. The fact that most Thais have reasonably accurate knowledge of AIDS and know that the disease is not transmitted through casual contact may also help explain why stigmatization of AIDS parents is not more widespread at the time of our research (Im-em et al. 2001).

## Conclusions

There are several major findings from our analysis that deserve emphasis. Probably the most important is that substantial numbers of older-aged persons are adversely affected by the AIDS epidemic through the infection of their adult children. Not only do these AIDS parents far exceed the number of older persons who are HIV infected themselves but, at least in Thailand, they far outnumber AIDS orphans, a group that has received extensive publicity and attention. Yet these older-aged AIDS parents have been largely overlooked by national governments, international organizations, and private organizations concerned with the epidemic .

AIDS parents can suffer a wide variety of adverse consequences as a result their adults child's illness and death. The only aspect of the situation of AIDS parents that has received some attention, however, is in their role in fostering orphaned grandchildren. But this is only one of many pathways through which older age AIDS parents can be affected and, in contexts such as Thailand, involves only a minority of older persons among those who lose their adult son or daughter to the disease. In other settings, particularly in high prevalence African countries, where the fertility levels of those in the ages most susceptible to AIDS is much higher, care for AIDS orphans will be more common. While the care of orphaned grandchildren remains an important pathway through which the epidemic affects older persons, its extent and consequences for grandparents is likely to vary substantially with the particular setting. Moreover, the almost exclusive emphasis on older people as foster parents for AIDS orphans gives the misleading impression that this is both the most common and most significant way that older people are affected, neither of which is necessarily correct.

At the same time that older-aged parents suffer adverse impacts they also make very substantial contributions in helping the society cope with the epidemic through the care-giving of their infected sons and daughters. Our results suggest that the majority of Thai adults with AIDS live with and are cared for by a parent by the terminal stage of the illness and in half of the cases, a parent serves as a main caregiver. This is very similar to findings from Uganda, the only other country for which a systematic assessment is available (Ntozi & Nakayiwa 1999). By providing care for their adult children at home, AIDS parents take a tremendous burden off the health care system. Our results also reveal that many of the adverse impacts experienced by parents are linked with their contribution as caregivers and are particularly pronounced in situations in which a parent acts as a main caregiver. Parents also often serve as critical links between their ill adult child and the health care system. They frequently accompany their infected son or daughter to health service outlets, stay with them in the hospitals, consult with health care providers about appropriate treatment, administer the prescribed medications, and provide a full range of personal care at home. Yet at present there is little recognition in Thailand or elsewhere of this major contribution of older-aged parents. Thus almost no programs exist that are designed to provide guidance to them as they carry out this arduous and painful role.

The in-depth interviews with AIDS parents clearly reveal the dedication with which most AIDS parents involved with caregiving carry out their role and their desperate wishes to reduce the suffering and improve the health of their infected sons and daughters. Older parents are thus ideally situated and

motivated to help in efforts to improve the quality of care of persons with HIV/AIDS. Their potential contribution is likely to increase in importance as new, more ambitious programs promote more extensive prophylaxis and treatment for opportunistic infections, complex antiretroviral treatment of HIV, and palliative care.

Overall, the loss of a child to AIDS has a serious economic impact only for a minority of AIDS parents. Those parents who spent substantial amounts on treatment tend to be economically better off than average and hence can afford to do so without lasting financial hardship. At the same time, the poor appear to be the most adversely affected. Even though they spent less on treatment, caregiving and funeral expenses, the amounts were more devastating for them relative to their economic resources. One implication of this finding is that interventions intended to help older-aged parents deal with the financial strains associated with losing an adult child to AIDS should take into account the considerable range of vulnerability that exists and target those who are particularly susceptible to resulting economic hardship.

Some potential impacts of losing an adult son or daughter to AIDS may not become apparent until long after the adult child's death. In particular, the full implications of the loss of a potential provider of care in old age or a contributor to material support may not become evident until the parents' health and physical stamina decline resulting in frailty and a need to depend on others for material support. Our research is likely to miss these potential long term effects because insufficient time had past at the time of data collection for them to manifest themselves. At the same time, as noted above, most AIDS parents have other surviving children on whom they can depend, reflecting the high fertility levels that prevailed in Thailand until several decades ago. Thus for many the loss of just one adult child may not seriously jeopardize their old age care and support from adult children. If the AIDS epidemic continues on any significant scale, however, the subsequent generations of AIDS parents will have had smaller families and the impact a losing even just one adult child could have a more extensive impact on support from children in old age. Moreover, in other settings such as in some African countries, where HIV prevalence is many times higher than in Thailand, even though parents may have experienced high fertility, they are at much greater risk of losing multiple children and thus more vulnerable to serious erosion of potential old age support from adult children.

Sustained social stigma directed at parents of persons who died of AIDS is far from universal in Thailand at present. Sympathetic and supportive reactions from others in the community are more frequently reported than negative ones. A recent survey in Zimbabwe also found that only a little over a fourth of older persons from households associated with AIDS (many of whom presumably are AIDS parents) reported experiencing stigma (WHO 2001). Clearly negative reactions are not absent in many community settings and our open-ended interviews revealed many such examples. However, it may be that anecdotal evidence of extreme negative reaction, especially during early stages of the epidemic, has led to an exaggerated and out-dated view of the predominance of stigmatization and to resistance to recognizing that community members can also be sympathetic and helpful to a family unfortunate enough to lose a member to AIDS.

One implication of the relative predominance of positive community reaction is that programs designed to build on community support in order to assist families with a member ill with AIDS or who have suffered an AIDS death would meet less resistance than might otherwise be thought. It also reduces what could potentially be an important barrier to home care by parents. A more accepting community attitude is likely to increase the willingness of an ill adult child to return home from elsewhere and that of the parents to accept responsibility for an AIDS inflicted son or daughter.

The particular culture, politics, and levels of socio-economic development of any setting as well as the dimensions and characteristics of the epidemic are likely to condition the nature and magnitude of its impact on older persons. Thailand shares important characteristics with many of countries with moderate to severe levels of the HIV/AIDS epidemic that are likely to condition the implications for parents and

families. These include the heterosexual nature of most transmission and the dependence of parents on adult children for old age support.

There are also features of the Thai situation that distinguish it from many other developing countries, particularly those in Africa where the severity of the epidemic is far worse. Many of these features are likely to moderate the impact of the epidemic on older-aged Thai parents compared to parents in other settings where they are absent. These include a well developed public health system, reasonably widespread availability of government health insurance, an unusually successful effort to openly confront the epidemic and to educate the public about it, and low fertility among the generation of adults in the prime AIDS ages combined with high past fertility of their parents. Moreover, Thailand has its own particular cultural setting, strongly influenced by its heritage of Theravada Buddhism, within which the causes and consequences of epidemic play out (Keyes 1987 ). Thus the findings of the present study are likely to have considerable relevance for other developing countries with AIDS epidemics but also need to be understood in terms specific to the Thai context.

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Table 1. Potential Pathways through which AIDS Epidemic Can Adversely Impact the Well-being of Parents of Adult Children with AIDS and their possible specific consequences.

Potential pathway	Dimension of well-being and possible specific consequence (see codes for possible specific consequence below)			
	Emotional/ psychological	Economic/ Financial	Physical health	Social
Caregiving	A B C	A	A B	A B C
Coresidence	A C	-	B	B
Providing financial/ Material support during illness	D	B C	C	-
Sponsoring the funeral	C D	B C	C	D
Fostering grandchildren	C D	B C	C	A B C
Loss of child	D E	D E	-	-
Negative community reaction	C	F	-	B D

Possible specific consequences  
(note PDA = person who dies of AIDS)

#### I. Emotional/psychological consequences

- A. psychological pain of seeing suffering and decline of PDA's health
- B. feeling overwhelmed by caregiving demands
- C. psychological pain from anticipated or enacted negative community reaction
- D. anxiety concerning consequences for economic security
- E. grief from loss of PDA

#### II. Economic/financial consequences

- A. opportunity costs of time taken from economic activities
- B. indebtedness from borrowing money to cover expenses
- C. depletion of savings or sale of assets to cover expenses
- D. disruption of PDA's contributions to parents' household
- E. loss of future support when parents are in old age
- F. loss of business from former customers out of fear of contagion

#### III. Physical health consequences

- A. physical efforts required by caregiving
- B. Risk of exposure to HIV (very low) or opportunistic diseases (esp. TB)
- C. Strain of additional economic activity needed to cover expenses

#### IV. Social consequences

- A. time taken away from social activities
- B. avoidance of social contact by others
- C. strained intra-familial relations
- D. strained social relations

Table 2. Age distribution of AIDS parents at time of adult child's illness, by source of data

Age at time of child's illness	Expected distribution according to national AIDS register (1997-99)	Parents reported by key informants	Parents interviewed in direct interview survey
< 50	15.2	15.5	13.3
50-59	35.3	38.5	36.9
60-69	34.6	35.1	35.8
70+	14.9	10.9	14.0

Table 3. Parental caregivers and instrumental helpers by gender

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

Notes: (a) [mother only + both parent]/[father only + both parents]

Table 4. Parental caregiving duration by return migration status of adult child who died of AIDS

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

Source: Direct interview survey.

Table 5. Percent of parents performing specific tasks of caregiving and instrumental help among parents who assisted their adult child with AIDS with either type of assistance.

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

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

Table 6. Health problems experienced during caregiving by parents who gave care to an adult child with AIDS

Health problem	All parents who assisted with personal or instrumental care			Parents who assisted but were not main personal caregiver (a)		Parents who were main personal caregiver	
	Total	Mothers	Fathers	Mothers	Fathers	Mothers	Fathers
a) Strained muscles	41.4	49.1	30.7	45.6	25.3	50.4	41.9
b) Headaches/stomachaches	31.0	34.6	25.9	29.2	20.8	36.7	36.5
c) Fatigue	55.5	60.6	48.2	50.0	39.0	64.8	67.6
d) Insomnia	68.7	74.9	59.9	70.8	52.9	76.5	74.3
e) Nervousness/anxiety	73.4	80.3	63.9	75.3	60.1	82.2	71.6

Notes: (a) includes parents who were main instrumental helpers but not a main personal caregiver.

Source: Direct interview survey

Table 7. Percent distribution of self reported change in health over last 3 years, comparison between parents who lost a child to AIDS and parents who did not

Self reported change in health over last 3 years	Both sexes		Fathers		Mothers	
	AIDS parents	Control parents	AIDS parents	Control parents	AIDS parents	Control parents
much better	2.2	3.7	1.8	4.0	2.5	3.5
somewhat better	8.2	10.0	7.0	6.9	9.1	12.5
about the same	31.0	34.2	37.5	39.3	25.9	30.1
somewhat worse	50.2	46.0	46.0	43.6	53.4	47.8
much worse	8.5	6.1	7.7	6.2	9.1	6.1
Total percent	100	100	100	100	100	100

Source: Direct interview survey

Table 8. Percent distributions of current state of happiness and change in happiness over last 3 years, comparison between control parents and AIDS parents

<b>Measure of happiness</b>	<b>Control parents</b>	<b>AIDS parents</b>
<b>Current level of happiness</b>		
very happy	8.8	3.8
somewhat happy	47.6	36.8
neither happy nor unhappy	27.4	34.8
somewhat unhappy	14.9	19.0
very unhappy	1.3	5.6
Total percent	100	100
<b>Change in happiness over past three years</b>		
much happier now	3.5	2.3
somewhat happier now	21.8	17.5
about the same	42.8	34.0
somewhat happier then	28.7	38.6
much happier then	3.2	7.6
Total percent	100	100

Source: Direct interview survey.

Table 9. Percentage of AIDS parents involved in the care and living arrangements of AIDS orphans

	Key informant study	Direct interview survey
<b>Percent of AIDS parents whose deceased son or daughter had a surviving child</b>	44.4/50.6 (a)	43.8
<b>Percent of AIDS parents who ever cared for an AIDS orphan</b>		
Among all AIDS parents	18.3(b)	31.3
Among AIDS parents whose deceased son or daughter had a child	34.4(b)	68.4
<b>Percent of AIDS parents who ever lived with an AIDS orphan</b>		
Among all AIDS parents	n.a.	25.7
Among AIDS parents whose deceased son or daughter had a child	n.a.	58.8
<b>Percent of AIDS parents who currently live with an AIDS orphan</b>		
Among all AIDS parents	n.a.	20.8
Among AIDS parents whose deceased son or daughter had a child	n.a.	47.5

Note: The unit of analysis for this table is an AIDS parent. In cases where both parents are surviving each counts as a case.

(a) The first figure shown is based on all cases for whom it was known that there was a surviving parent; the second figure is based on the parents of the subset of persons who died of AIDS for whom the key informant provided supplemental information.

(b) Result based on parents of the subset of persons who died of AIDS for which the key informant provided supplemental information.

Table 10. Potential influences on economic impacts on AIDS parents, by caregiving and economic status

% of cases of adult children who died of AIDS in which	All cases	Was a parent a main caregiver?		Economic status		
		No	Yes	Better off	Average	Poorer
<i>A parent was a main caregiver</i>	71.3	0.0	100.0	69.3	70.2	72.7
<i>A parent was a main contributor to expenses during adult child's illness</i>	61.9	38.9	71.2	70.7	67.2	54.5
<i>A parent had to curtail economic activities</i>	47.0	23.9	56.2	41.3	46.6	49.2
<i>Parents helped pay for funeral any net cost</i>	69.5	61.9	72.6	69.3	80.2	62.0
<i>substantial net cost (5000+ Baht)</i>	57.1	46.4	61.3	64.0	69.2	45.5
<i>Parents provided support to dependents of deceased adult child</i>	31.6	29.2	32.6	36.5	30.5	30.6
<i>Parents went into debt to pay to pay expenses</i>	38.6	26.5	43.4	30.7	37.4	42.8
<i>Parents sold property or possessions to pay expenses</i>	20.1	15.0	22.1	16.0	20.6	21.4
<i>The deceased adult child contributed to parental household income during year prior to death any contribution</i>	71.3	66.4	73.3	64.0	65.6	78.6
<i>main contributor</i>	32.2	28.3	33.8	17.3	26.0	42.8

Source: Direct interview survey.

Table 11. Percent distribution of community reaction to AIDS parents during the illness and after the death of their adult child, by caregiving status

Type of reaction	During the illness			After the death		
	All cases	Was a parent a main caregiver?		All cases	Was a parent a main caregiver?	
		Yes	No		Yes	No
only positive	67.6	67.4	68.2	74.7	73.9	76.6
some negative but mostly positive	14.2	14.9	12.7	11.5	13.2	7.2
mostly/only negative	7.3	8.3	4.5	4.2	5.1	1.8
neutral/other	10.9	9.4	14.5	9.7	7.7	14.4
Total percent	100	100	100	100	100	100

Source: direct interview survey

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

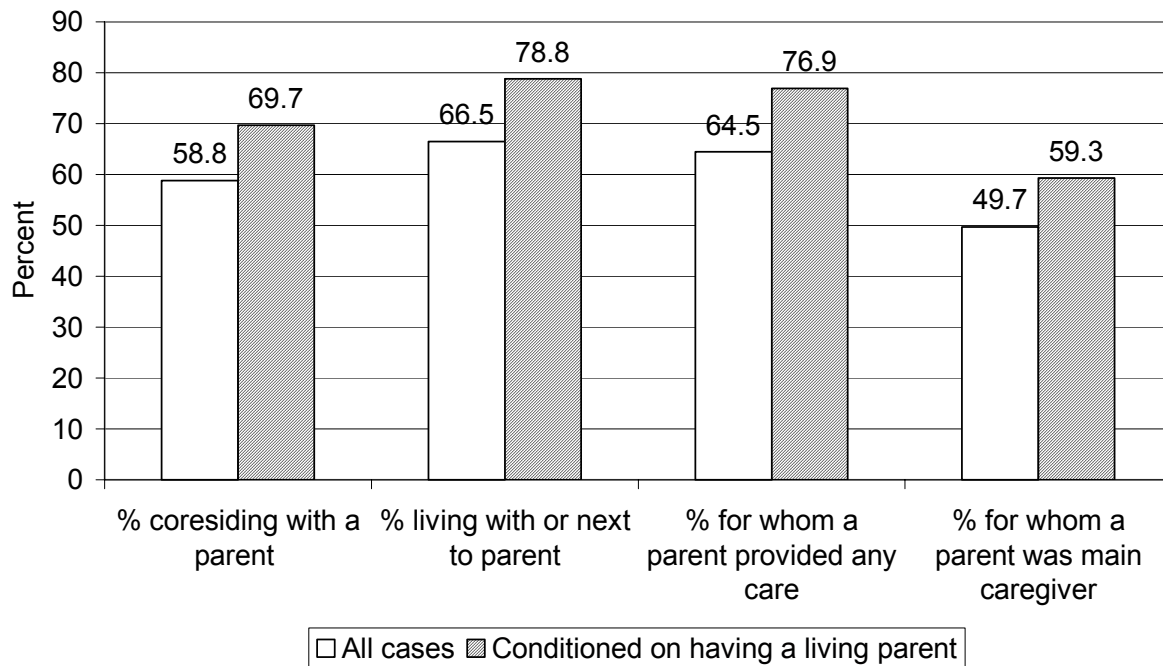


Figure 2. Percent who moved back to home community after the onset of symptoms among adult children who died of AIDS and were cared for by parents

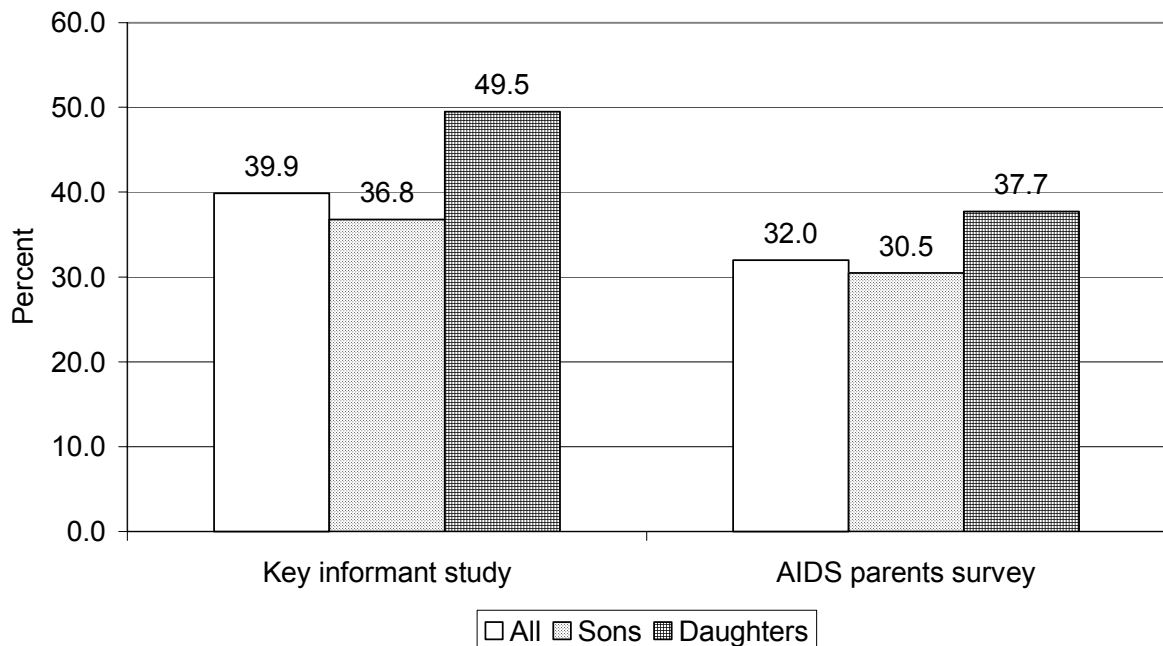
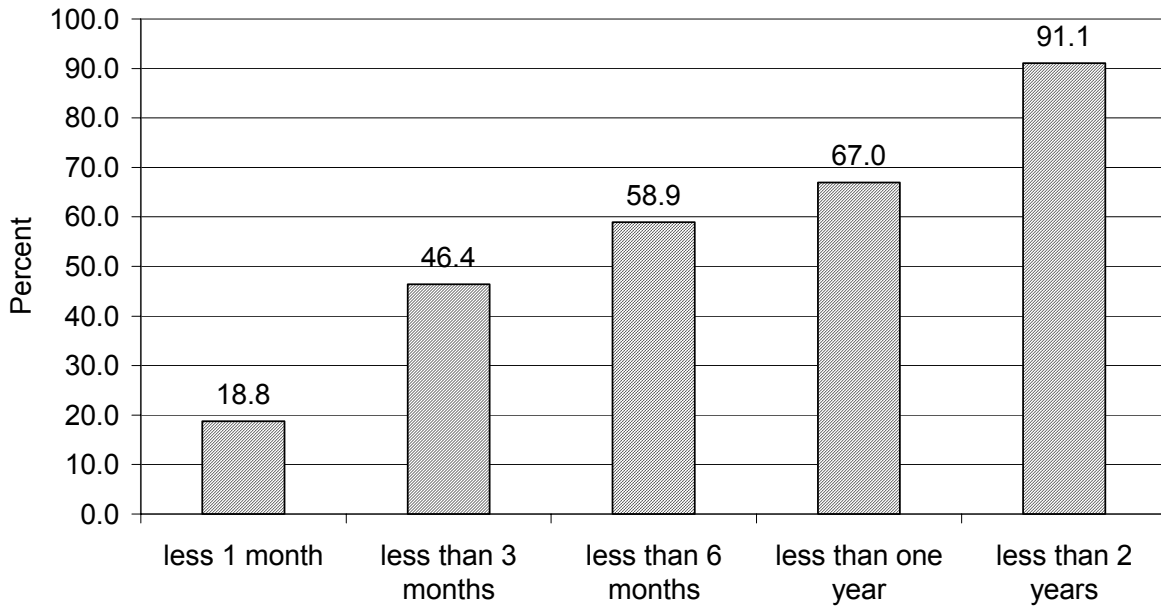
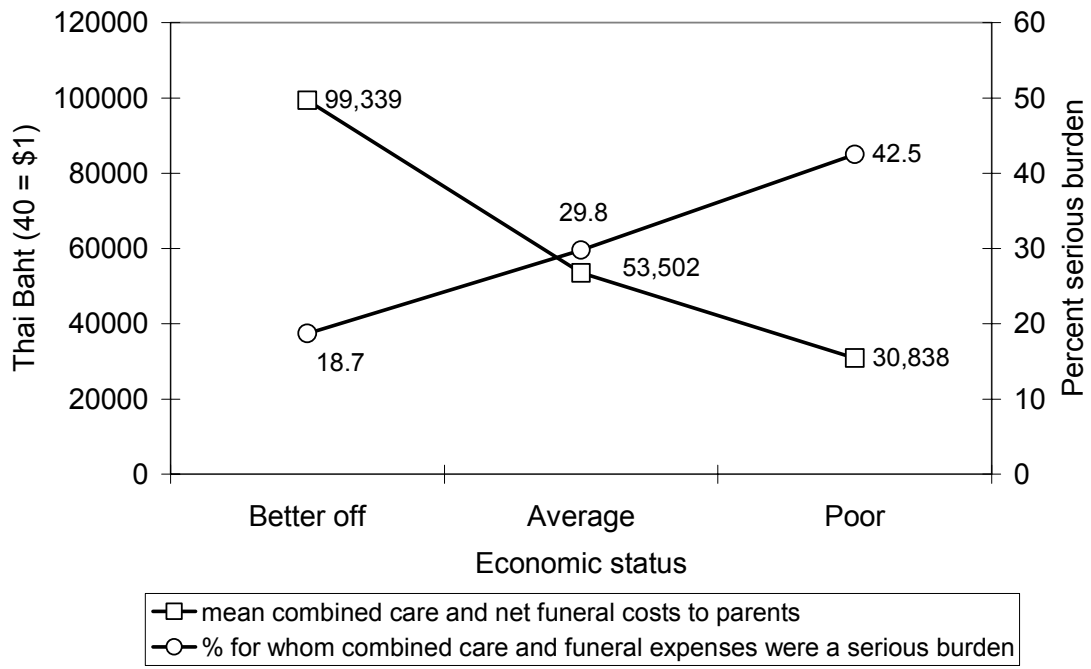


Figure 3. Percent dying within specified time after reurning ill among adult children cared for by parents



Source: AIDS parents survey

Figure 4. Mean combined care and net funeral costs to parents and percent for whom costs were a serious burden (source: AIDS parents survey)



-□- mean combined care and net funeral costs to parents  
 -○- % for whom combined care and funeral expenses were a serious burden