



Research Report

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The Impact of AIDS on Older-age Parents
in Cambodia

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Executive Summary of Main Findings

Most adults who die of AIDS have older-aged parents who survive them. This, the first quantitative study in Cambodia to look at the impact of the death of a child due to AIDS on their older parents, directly contributes to “improving data collection and analysis on the status, trends and socioeconomic impact of the epidemic,” a recommendation specifically set out by Cambodian government in their efforts to meet the United Nations Millennium Goals. Findings from this study can inform policy aimed at mitigating the impact of the epidemic on older persons. Some of the significant policy relevant findings from this study are:

1. Older adults who have experienced the death of a child due to AIDS in Cambodia almost universally play a key role during the child’s illness. Almost 80% were among the main persons who provided direct personal care. The average length of the care period was over 7 months. Just over 60% lived with the AIDS victim at the terminal stage of illness. A substantial majority provided assistance with expenses.
2. The involvement of parents in their children’s illness crosses demographic lines. Parents provide assistance whether they live in rural or urban areas, whether they are married or unmarried, and whether they are poor or not.
3. More than half of the children dying of AIDS left behind orphans who frequently live with and receive support from their old age grandparents.
4. Expenses related to an AIDS illness and death can be a considerable drain on resources amongst older adults already facing harsh economic conditions. Three-quarters of those that supported a child reported the expenses to be a serious burden. Moreover, in most cases the child that died had provided material or physical support to the elderly person. In many instances, the deceased child was the main provider of material support.
5. Despite the burden faced by older Cambodians caring for a child with AIDS, formal assistance is not often available. Only one-quarter received any assistance from formal sources, mostly from NGOs and only very rarely from government sources. It is a particular concern that those among the poorer half of the sample were the least likely to receive formal assistance.
6. Multivariate analyses confirm that the loss of a child due to AIDS results in a reduction in economic well-being. Parents experiencing an AIDS death are more likely to report that their economic condition worsened during the prior three years compared to those who lost a child to other causes or those who did not experience the recent death of a child. Those experiencing an AIDS death also owned fewer liquid assets than others, consistent with reports from a substantial share of respondents that those assets were sold in order to pay for expenses related to the illness and death of their child.

Introduction

The global AIDS epidemic is not only devastating for individuals who become infected but can also adversely affect their families (United Nations Population Division 2003; WHO Regional Office for Europe's Health Evidence Network 2005). Considerable attention has been focused on AIDS orphans, the young children who are left behind (UNAIDS, UNICEF & USAID 2002). At the same time, survivors also include the parents of those dying of AIDS, who are typically individuals approaching or are already in elderly ages. Yet, these AIDS parents, as we refer to parents of people with AIDS, receive far less attention and are infrequently the subject of research. Some mention has been made of their role as foster care providers to orphaned grandchildren, and more recently their critical role as caregivers for their infected adult children (United Nations 2002; UNAIDS 2004). However, compared to other subgroups within society, older adults have been largely ignored with respect both to how they are affected and how they could contribute to combating the epidemic and ameliorating its consequences (HAI 2005b). This is the case even though the numbers of older persons affected is extremely large given that most adults who succumb to AIDS have at least one and often two surviving parents (Knodel & VanLandingham 2002).

The general lack of research on the impact of the AIDS epidemic on older persons and specifically on parents of afflicted adults both reflects and contributes to their lack of saliency in discussions of the epidemic. Several studies using participatory and qualitative research methods in Cambodia, Tanzania and Thailand suggest widespread impacts on older persons who are part of households affected by HIV/AIDS (HAI 2004a, 2004b, 2005a; Saengtienchai & Knodel 2001). With the notable exception of a comprehensive multi-method study conducted in Thailand, however, systematic quantitative assessments are rare.¹

The present study examines the impact of the epidemic on the older-age parents of adults who died of AIDS in Cambodia. As such it directly contributes to "improving data collection and analysis on the status, trends and socioeconomic impact of the epidemic," a recommendation specifically set out by Cambodian government in their efforts to meet the United Nations Millennium Goals (Cambodia, Ministry of Planning 2003). Results are based on survey interviews in 2004 and 2005 that included a series of questions modeled after those used in the Thai research. It represents one of the few quantitative assessments of the impact of AIDS on older persons anywhere and the first for Cambodia. An important strength of the study is that it permits assessing a range of consequences that can occur not only during the period of illness but also following the death of the person with AIDS. This is particularly important for two reasons. First, as research in Thailand has revealed, parental caregiving is often concentrated at the terminal stage of illness. Thus studies of caregiving of persons still living with HIV/AIDS will underestimate parental involvement by missing contributions of parents that are initiated only at the very late stages of illness. Second, many potential impacts occur only after the death of the adult child (Knodel 2005). The data also permit comparisons between the impact of adult child deaths due to AIDS and those from other causes as well as comparisons with older persons who have not experienced the recent loss of an adult child.

Our analyses are divided into two main sections. The first examines outcomes specific to respondents who experienced a recent death of an adult child with a focus on those whose child died of AIDS. An AIDS death is identified either by the parent's self-report or through a set of questions designed to identify likely AIDS cases. Therefore, AIDS deaths are either stated or suspected. Comparisons with those whose child died of other illnesses are also explored. The second section examines outcomes relevant to all respondents and compares those who experienced no recent adult child death with those who lost a child to AIDS and to other causes. Before turning to findings, we describe some relevant aspects of the Cambodian setting, present a conceptual framework that guides our analysis, and discuss issues regarding data and measures.

Setting

Socioeconomic and demographic situation. As of 2005, Cambodia's population was 13 million of which 15 percent lived in an urban area (PRB 2005). As signified by the UN classification of Cambodia as one of the world's "least developed countries", the population is extremely poor. In Southeast Asia, only Laos scores lower on standard economic measures. Over three fourths of the population live on less than two dollars a day, a level similar to the average for Sub-Saharan Africa. In part the pervasive poverty is a legacy of the conflict that engulfed Indochina several decades ago. After years of civil strife, the Khmer Rouge took complete control of the country in 1975 and for almost 4 years carried out a radical and brutal revolution during which as much as a fourth of the total population died from violence, starvation and disease (Heuveline 1998; Kiernan 2003). Many who perished were the sons, daughters, and spouses of today's older-aged population (Zimmer, Knodel, Kim, & Puch 2006). In early 1979, Vietnam invaded pushing the Khmer Rouge into remote enclaves and occupied the country for a decade. Only in recent years, following elections supervised by the United Nations in 1993, has relative peace prevailed. Even so, socio-economic development has been slow.

Cambodia ranks low on United Nations Human Development Index. Consistent with high levels of poverty, social protection measures in Cambodia are underdeveloped and under-funded and the public health system is generally characterized as poorly functioning (Buehler et al. 2006; Chan and Ear 2004; Coates 2005). However, the health system's response to the AIDS epidemic, including care and treatment, has been remarkably aggressive and effective, especially since the adoption and implementation of the comprehensive 'Continuum of Care' framework in 2003 (Buehler et al. 2006; UNAIDS 2006; Vun 2006; WHO 2006). Through a partnership between the Ministry of Health and NGOs home- and community-based care expanded from modest levels a few years ago to much more extensive coverage recently and is continuing to do so. As of June 2006, well over half of persons in need of anti-retroviral treatment are estimated to be receiving it, making Cambodia one of the most successful countries in the developing world in this respect. However the bulk of these achievements occurred after the most of the period covered by our study and thus are not reflected in our results.

Except for the Khmer Rouge period, total fertility in Cambodia remained above 5 births per woman until shortly before 2000. As a result, most older persons have at least several living children despite the common loss of children during the Khmer Rouge period (Zimmer, Knodel, Kim & Puch 2006). Even ignoring the Khmer Rouge period, life expectancy at birth has been slow to improve, increasing over the

past two decades by only 4 years to its present level of 56. As a result of these demographic trends, older persons constitute a relatively small share of the total population. According to the 2004 Cambodia Inter-censal Population Survey (CIPS), only 5.9 percent of the Cambodian population is aged 60 and over. One unusual feature of today's Cambodian older population is the large predominance of women (59 percent in 2004), reflecting in part the disproportionate share of men among those killed under the Khmer Rouge. The relatively low share that elders make up of the total population, however, masks the fact that almost one in four households has at least one member who is age 60 or older (original tabulations from the 2004 CIPS).

Filial support of elderly. As is common in much of Southeast Asia, older persons in Cambodia tend to live with adult children and depend on them for much of their support (Kato 2000; Zimmer & Kim 2001). Levels of coresidence are extremely high, even on Asian standards, with approximately four out of five elderly Cambodians living with at least one child and almost 60 percent living with at least one married child, who more often is a daughter than a son (Knodel, Kim, Zimmer & Puch 2005). Indeed given the lack of welfare measures, elderly Cambodians have little choice but to depend on material and physical support from their families and particularly from their children. Almost two-thirds of Cambodians aged 60 and older, and four-fifths of those aged 70 and above, report that their children are the main contributor to the support of their households. The vast majority of older Cambodians also receive money or other material support from children living outside the household although the monetary value of the support is typically modest, reflecting the pervasive poverty characterizing both generations. Cambodian elders also provide some support to their adult children although in lower proportions than the flow in the opposite direction.

AIDS epidemic. Most global attention to the AIDS epidemic focuses on Sub-Saharan Africa where almost two-thirds of persons living with HIV worldwide are found (UNAIDS 2006). Still almost a fifth of HIV positive persons in 2005 are estimated to live in South and Southeast Asia making the region second in numerical importance worldwide. Within the region, Cambodia has the highest adult prevalence level, currently estimated at 1.6% by UNAIDS (2006), down from a peak of 3% (Buehler 2006). Although well below levels in most Sub-Saharan African countries, the absolute numbers of persons dying of AIDS in Cambodia is substantial and thus so are the number of older persons who lose an adult son or daughter to the epidemic. According to the baseline scenario, recent projections indicate over 90,000 adult deaths due to AIDS between 2000 and 2005, with the vast majority between ages 20 and 49 (Cambodia Working Group on HIV/AIDS Projections 2002). Original tabulations from the Cambodia Inter-censal Population Survey 2004 indicate that 78% of this age group has a living mother. If we also consider that many have a surviving father, it becomes clear that large numbers of older age Cambodians have suffered the loss of an adult son or daughter in the course of the epidemic.

Analytical Framework

The AIDS epidemic can have adverse consequences for parents of those who become ill and die. Perhaps most universal is the emotional devastation and lasting grief that the loss of an adult child brings parents. Our analysis is guided by a general conceptual framework that identifies seven pathways and their

potential consequences for economic, physical, emotional, and social well-being.² The framework is described in more detail elsewhere (Knodel, Watkins & VanLandingham 2003).

Living arrangements. Adult children who die of AIDS may live with or near their parents during the time of illness. Witnessing the suffering and decline of their child is virtually certain to result in considerable psychological pain. Coresidence is also often associated with caregiving and financial support, can also put a parent at risk of exposure to opportunistic infections associated with AIDS (especially TB), and can curtail normal social life if neighbors avoid contact.

Caregiving. Providing care to an ill adult son or daughter demands enormous time and effort, especially at the terminal stage of AIDS, and may compete with time needed to earn a livelihood as well as divert time from social activities. Some caregiving tasks, such as lifting the ill adult child, may lead to physical strains. Social shunning could result if community members have misgivings about being near a caregiver. Intra-familial relations can become strained if caregivers perceive inequities in the contribution of other family members.

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 savings, or sell assets to cover these unanticipated expenses. 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 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 can suffer socially and emotionally.

Fostering grandchildren. AIDS Parents may inherit responsibility for orphaned grandchildren with obvious financial implications. Emotional strains may result if there is negative community reaction towards AIDS orphans. Physical strain and exhaustion can result from additional work required to cover these costs and care of the orphans. Caring for a grandchild, however, may also be emotionally fulfilling for the bereaved AIDS parent (Saengtienchai & Knodel 2001).

Lost support. 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 future support that the deceased child might have provided in their old age.

Community reaction. Negative reactions of community members towards the parents, either during the time of the child's illness or following the death, could cause social isolation. Fear of contagion may lead customers to stop patronizing businesses run by the parents, especially if the ill child lives with or is cared for by the parents.

The extent to which these potential impacts actually occur is a matter to be determined by systematic empirical research. Impacts are likely to be context sensitive and vary across different settings. In addition, the death of an adult child due to any cause can have many of the same effects. However the impact of an AIDS death may be particularly severe given the prolonged periods of illness and disability and possible negative community reactions that may be less associated with other causes. Whether this is the case is also a matter for empirical investigation and is addressed in the present study.

Data and Measures

Sources. Data for the present study come from the 2004 Survey of Elderly in Cambodia (SEC) and a supplemental survey in 2005. The original survey consisted of 1273 interviews with a probability sample of persons aged 60 and over living in Phnom Penh province, which contains both the city and its rural environs, and five other provinces. These six provinces are Cambodia's most populous and together contain over 50 percent of the population. A detailed description of the sampling procedures and response rates is available elsewhere (Knodel, Kim, Zimmer, & Puch 2005). The supplemental survey involved 103 interviews with purposively targeted people age 50 and older who lost an adult child within the last five years to an illness (although not necessarily AIDS) in Phnom Penh and in all but one of the five other provinces included in the original survey.³

Similar questionnaires were administered in both the original and supplemental surveys.⁴ The questionnaires covered standard issues about elderly economic, social and physical well-being that are the focus of recent surveys of older age populations in the region as well as questions on the impact of illness and death of adult children, and awareness and knowledge of older persons regarding AIDS. Respondents who experienced the loss of an adult child (age 16 or over) during the prior five years were asked questions about the role of the parents in caregiving, the opportunity costs involved, payment of health care, medicines, treatment, and funeral expenses, and fostering orphaned grandchildren. These respondents were also asked if the illness and death of the child created economic difficulties for them and if it led to the sale of assets, debt, or extra employment. If more than one adult child died during the prior five years, the questions focused on the most recent. In total, information regarding the impact of an adult child death was collected for 216 respondents (113 in the 2004 SEC and all 103 in the 2005 supplemental sample which targeted such cases). In addition, all respondents were asked about their current economic and psychological well-being and recent changes in their economic situation.

Identifying AIDS deaths. To identify the cause of an adult child's death as AIDS, we rely on a combination of direct replies by parents that the cause of death was AIDS and responses to several "verbal autopsy" questions, an approach used successfully in a number of other settings (Doctor & Weinreb 2003). As table 1 indicates, of the total 216 cases in the combined original and supplemental surveys who experienced the death of an adult child within the previous 5 years, 90 respondents stated the cause of death as AIDS and an additional 28 were classified as suspected AIDS cases.⁵ We suspect almost all deaths parents attributed to AIDS are actually due to AIDS. Although suspected cases based on symptoms are less certain, they constitute only a minority of the total cases classified as AIDS deaths.

Table 1: Number of cases by death of children status and source of data

Death of children status	Original SEC (2004)	Supplementary sample (2005)	Total
Total	1273	103	1376
No death	1160	0	1160
Recent adult child death	113	103	216
Stated AIDS death	20	70	90
Suspected AIDS death	19	9	28
Death from other illness	57	24	81
Death from non-illness	17	0	17
<i>Sub-total of stated and suspected AIDS deaths</i>	<i>39</i>	<i>79</i>	<i>118</i>
<i>Sub-total of non-AIDS deaths</i>	<i>74</i>	<i>24</i>	<i>98</i>

As noted above, we are interested in comparing respondents whose adult child died of AIDS with those whose child died of another cause as well as with respondents who did not experience either event. Deaths due to causes other than an illness include fatal accidents or violence and thus may be sudden and not require significant care-giving or medical expenses. As table 1 indicates, among the original SEC sample, 1160 respondents reported no death of an adult child in the past five years and of the 113 who reported a death, 20 were stated as AIDS and another 19 are suspected AIDS cases. Among the 74 non-AIDS deaths, 57 were due to an illness. By design, all 103 respondents in the supplemental survey had experienced a recent adult child death either due to AIDS or some other illness. In contrast to the SEC, stated AIDS cases in the supplemental survey far out number suspected AIDS cases and together far exceed non-AIDS deaths.

Sampling bias. The original 2004 SEC covered a general probability sample of households that should yield unbiased estimates of the proportions of parents who experienced the recent loss of an adult child. Interviewing a general sample of older persons, however, is inefficient for obtaining sizeable samples of parents who recently lost an adult child to AIDS or other causes, particularly in populations such as Cambodia where HIV prevalence is modest. It is for this reason that we added a supplemental non-probability sample targeting only such persons. Local informants often helped identify qualified respondents, which in turn likely biased the supplemental sample towards parents whose child died locally as well as those whose child had died of AIDS and were willing to admit it.

Earlier research in Thailand indicated that many local informants can relatively easily identify parents in the community whose adult children died locally including those whose child died of AIDS but, because they are less aware of non-local deaths, have difficulty identifying local parents whose adult child died elsewhere (Knodel, VanLandingham, Saengtienchai, Im-em Wassana, & Kespichayawattana 2003). This also appears to be the case for the Cambodian supplemental sample. For obvious reasons, parents whose child died locally (either because the child already lived locally before becoming ill or had returned home due to illness) are more likely to be involved in caregiving and in paying associated expenses than parents whose child remained elsewhere as well as to experience other related outcomes of interest.

It also appears that the cases identified for interview in the supplemental sample are skewed towards those in which AIDS is the cause of death and in which the respondent was open about this. Local persons who helped identify cases for interview likely became aware of our interest in the impact of AIDS deaths when initially briefed about the study's purpose and thus tended to direct interviews to such cases. Additionally the fact that an adult child died of AIDS is more likely to be known in a community if the parents are open about it. If such cases differ with respect to outcome variables from cases where parents are not open about AIDS as the cause of death, additional bias could arise, although probably less severe than from the under-representation of parents whose children died outside the locality.

The sampling bias created by using informants to identify older age respondents who recently suffered the death of an adult child is clearly apparent from a comparison of results from the original SEC and the supplemental survey that targeted such cases. Table 1 already makes clear that openly stated AIDS deaths are far more common in the supplemental than SEC sample among respondents who recently suffered the loss of an adult child. As table 2 shows, in the original survey, 32 percent of respondents who reported the death of an adult child during the prior 5 years indicated the child was living outside the parents' locality at the time of death compared to only 7 percent for the supplemental sample. In contrast far higher percentages of cases in the supplemental sample involved coresidence of the deceased adult child with the parents at the time of death than was found in the original SEC sample. Moreover, parental caregiving is far more common among those in the supplemental sample than the original sample. The contrasts are somewhat modified but are still clear when only those cases in the original sample are considered in which the adult child death was due to illness.

Table 2. Residence of adult child at death and caregiver status of parents by source of data

% of cases in which:	Source of data		
	Supplemental sample	Original SEC sample - all deaths	Original SEC sample - deaths due to illness
The deceased child lived outside the locality at time of death	6.8	31.9	28.9
The deceased child coresided with parent at time of death	84.5	46.9	50.0
A parent provided some personal or instrumental care to deceased child	94.2	61.9	72.2
A parent was a main personal caregiver to deceased child	92.2	50.4	58.9
A parent was a main instrumental caregiver to deceased child	86.4	48.7	56.7
A parent paid some medical expenses	76.7	53.1	58.9
A parent was primary source of medical expense payments	68.9	29.2	32.2
Base N of cases	103	113	90

Even the original SEC results make clear that there is extensive involvement of parents in coresidence, caregiving and contributing to the expenses of adult children who become fatally ill in Cambodia. While much of our subsequent analysis of impacts is based on combined SEC and supplemental sample data, and thus is skewed towards those involved in caregiving, the subsets that provide care or co-reside with children clearly represents a very substantial share of AIDS parents. Presumably, results that are conditioned on caregiving or other types of involvement should at least provide reasonable estimates for these important subsets of parents.⁶

Interviewer effects. An additional concern for our analysis stems from potential interviewer effects. While the original SEC involved a team of over 20 interviewers only two conducted the supplemental sample interviews, one of whom was part of the original team. Some evidence suggests that the responses solicited by the two supplemental sample interviewers may differ in their distribution, particularly for some attitudinal questions, compared to the average distribution for other interviewers.⁷ If these distributional differences are due to an interviewer effect, it could potentially bias comparisons between respondents who experienced the death of an adult child due to AIDS and those who experienced one due to other causes since, as noted above, the former are disproportionately represented in the supplemental sample relative to the latter. For this reason, results are statistically adjusted for the source of data when comparing these two groups.⁸

Measures of economic well-being. A key component of the framework we employ is the notion that illness and death of an adult child with AIDS may adversely impact the economic situation of the parents and, in addition, that the parents' economic status prior to the illness may influence other outcomes of interest. Therefore, in our analysis, economic status is treated at times as an independent variable and at times as a dependent variable. A concern that we need to address is that most measures of current economic status will reflect not only the economic situation that existed prior to their child's illness but also any impact the illness or death subsequently had on the parents' economic situation. To isolate the impact of an illness and death it is necessary to adjust for economic situation earlier in time, and therefore measures are needed of parents' economic situation prior to when any impact would have occurred. In addition, measures of past economic situation are required in order to examine whether economic status has an impact on the response to an illness and death.

One way to address this concern is by distinguishing between liquid and non-liquid assets (Linnemayr 2005). The survey solicited objective information that relates to both relatively liquid possessions such as vehicles, household appliances and jewelry (e.g. gold) that could be sold by themselves to raise money to cover expenses at a time of crisis as well as information about fixed aspects of the housing unit that are not marketable by themselves. The latter can be considered relatively non-liquid, as it is reasonable to assume that parents are unlikely to sell their entire residence to cover the types of costs considered in the present study. Evidence from Africa confirms that these types of fixed assets are not affected by AIDS-related deaths (Linnemayr 2005). Thus these non-liquid items are used to construct an economic status measure that is largely free of effects from the illness and death of an adult child and are suitable to form a measure for use as an independent variable. We illustrate this issue in Appendix A.

We consider three non-liquid items associated with the respondent's dwelling: the type of toilet facility, the type of flooring, and the type of roof. For each item, the response categories reflect a reasonably clear hierarchy from poorer to better quality and are scored accordingly.⁹ Principal component analysis is employed to create a summary economic status scale based on non-liquid assets (see Filmer & Pritchett 2001). Factor scores were used to create a non-liquid asset score, which was re-calculated according to percentile rank so that the scale runs from 0 to 100, with the mean being 50. The higher is the score, the higher is the economic status. A dichotomous measure of poverty status is also formed by regrouping the scores according to whether they fell in the lower or upper half.¹⁰

A liquid asset score was calculated following a similar procedure. We based the measure on five items that did not depend heavily on the community having access to electricity since this is more a function of place of residence than individual household economic status. The items included are possession of jewelry and four household possessions: radio, television (which can be powered by a car battery), motorcycle and automobile. This measure presumably is not independent of the impact of the illness and death of an adult child since any of its constituent items could be sold to cover associated expenses. As such it is suitable as a dependent variable.

Several subjective measures are also included in the questionnaire. Two of these that are likely influenced by changes due to the illness and death of an adult child are also treated as dependent variables in the subsequent analysis.¹¹ The first measures economic well-being based on the question "how satisfied are you with your present economic condition?" Five possible answers ran from very unsatisfied (score of 0) to very satisfied (score of 4). The second measure indicates recent change in the respondent's economic situation based on the question "over the last 3 years would you say your economic situation has become better or worse?" Answers run from much worse (score of 0) to much better (score of 4).

Results

Our presentation of results begins by comparing respondents who lost a child to AIDS and those whose child died from another cause. We then concentrate on situations involving an AIDS death, first comparing some basic results for Thailand and Cambodia and then examining differences among Cambodians with respect to a wider range of outcomes according to place of residence, marital status and poverty status. Potential differences along these dimensions are of interest for several different reasons. Previous analysis of the SEC data reveals substantial differences in numerous social, economic and demographic characteristics between urban and rural elderly Cambodians (Knodel, Kim, Zimmer, & Puch 2005).¹² Marital status is potentially important since a married elderly couple may be better situated to cope with the care an ill adult child than would a widowed parent. In addition, there is considerable interest in the extent to which the impact of the AIDS epidemic on individuals and households is conditioned by poverty (United Nations Population Division 2005). Our presentation of results ends by comparing respondents who lost a child to AIDS, those who lost a child to other causes, and those who experienced no recent adult child death in order to assess the impact of child loss on economic well-being.

Table 3. Living arrangements, parental caregiving, parental payment of expenses, and former support from deceased child, by cause of child's death

	Original SEC sample only		Combined SEC and supplemental sample (statistically adjusted for source)	
	AIDS death	Non-AIDS death	AIDS death	Non-AIDS death
Base N of cases	39	74	118	98
The deceased child lived outside the locality at time of death (%)	28.2	33.8	16.6	22.5
The deceased child coresided with parent at time of death (%)	61.5	39.2*	72.6	57.2*
A parent provided some personal or instrumental care to deceased child (%)	92.3	45.9***	94.4	63.2***
A parent was a main personal caregiver to deceased child (%)	79.5	35.1***	87.4	56.0***
A parent was a main instrumental caregiver to deceased child (%)	64.1	40.5*	77.7	56.2***
A parent paid some medical expenses (%)	69.2	44.6*	76.8	50.4***
A parent was primary source of medical expense payments (%)	38.5	24.3	55.5	39.1
A parent had net funeral expenses (%)	66.7	63.5	77.8	66.2+
A parent paid medical and/or funeral expenses (%)	76.9	71.6	85.2	73.8+
The deceased child received assistance during time of illness or injury (%)				
From any formal source	38.5	24.3	29.9	16.0*
From an NGO	17.0	4.1**	19.1	3.5**
Deceased child provided support for parental household (%)	51.3	73.0*	53.2	69.7*
Deceased child was main supporter of parental household (%)	30.8	48.7+	41.9	44.4
Deceased child helped in chores in parental household (%)	51.3	51.4	54.6	57.7

Statistically adjusted results represent mean predicted probabilities based on logistic regression controlling for source of data (SEC or supplemental sample).

Significance levels (two-tailed tests): +=.10; * =.05; **=.01; ***=.001; n.s.=not significant at .10 level; n.a.=not applicable.

Comparison of AIDS and non-AIDS deaths. Table 3 compares living arrangements just prior to the death, caregiving, payment of expenses and loss of support among respondents who lost an adult child to AIDS and those whose child died of some other cause.¹³ Results are shown based on the original SEC sample only as well as on the combined SEC and supplemental sample. As discussed above, results based on the SEC alone are of particular interest given that they are unbiased. The combined results, however, have the advantage of being based on larger numbers. Moreover, even though they are skewed towards greater parental involvement, this should be true regardless of cause of death. Hence they may still

provide a reasonable assessment of differences in the implications AIDS and non-AIDS deaths. To control for possible interviewer effects referred to above, the combined results are statistically adjusted for source.¹⁴

As already noted, the original SEC results make clear that parents are extensively involved with adult children who become fatally ill or injured in Cambodia. Table 3 shows that according to the SEC sample there is little difference by cause of death in the percent whose child lived outside the locality at the time of death. At the same time, those whose children died of AIDS are substantially more likely to have the child coresident in their parental household just before the child died. AIDS parents are also generally more likely to provide care and pay expenses. These differences are apparent both when based on SEC alone and when based on the combined samples.

According to the original SEC results, just over three-fifths of respondents whose adult child died of AIDS were living with the child when the child died compared to only two-fifths of cases involving non-AIDS deaths. This in part appears to be due to a greater share of children who died of AIDS having moved back from elsewhere to be with the parents than in cases of those dying of other causes. Presumably many of the children who returned did so to receive parental care. Based on the combined SEC and supplemental sample results, 30% of children who died of AIDS in the locality compared to only 14% of those who died from other causes had returned from elsewhere prior to becoming ill or injured (results not shown). The share who returned from elsewhere among adult children who died of AIDS in their parents' locality is similar to that found in Thailand (Knodel & VanLandingham 2003).

Both personal and instrumental caregiving are more common among parents whose child died from AIDS than among those who lost a child to other causes. Personal care refers to assistance with items such as eating, bathing, dressing, cleaning wounds, and going to the toilet while instrumental care involves activities outside the home such as providing transportation, visiting health care facilities, and buying medicines. The non-AIDS cases include deaths due to accidents or violence, some of whom likely did not need care because death was immediate but even when such deaths are excluded, the differences in parental caregiving levels are still substantial (results not shown).

Parents also more commonly take responsibility for medical expenses in cases where the child died of AIDS versus other causes. However differences in the proportion of parents who had net funeral expenses are less evident, particularly for the original SEC sample. In any event, involvement of parents in paying either medical or funeral expenses for their deceased adult children in Cambodia appears to be very high regardless of the cause of death. There is some suggestion that formal sources of assistance (e.g. from the government, community, or NGOs) are more common among AIDS parents than parents whose child died from another cause, although the overall difference is fairly modest. A much stronger difference is evident, however, when only assistance from NGOs is considered possibly reflecting the expanded NGO program to provide home care funded by major donor organizations described above. Loss of financial support from the child appears to be more common in cases where the child died of other causes than AIDS while no difference by cause of death is apparent in terms of loss of assistance with household chores.

In sum, Table 3 shows several ways in which older aged parents play an important role in the care and treatment of all children who die, but it also highlights the fact that parents are more likely to be involved when the cause of illness is AIDS rather than some other cause. Nearly all older adults that had a child die of AIDS provided some personal or instrumental care prior to the death, a large majority reported they were the 'main' caregiver, about two-thirds were actually living with their ill child prior to the death, and most report paying for medical and funeral expenses.

Table 4. Orphaned minor children and their foster care arrangements, by cause of child's death

	Original SEC sample only		Combined SEC and supplemental sample (statistically adjusted for source)	
	AIDS death	Non-AIDS death	AIDS death	Non-AIDS death
Base N of cases	39	74	118	98
The deceased child left behind one or more children under age 16 (%)	56.4	59.5	61.6	54.3
Among cases in which a minor grandchild was orphaned, the orphan ever lived with the respondent (%)	63.6	45.5	78.5	53.3**
Among cases in which a minor grandchild was orphaned, the orphan was ever supported by the respondent (%)	68.2	56.8	78.8	59.0*
Among cases in which an orphaned grandchild was supported by the respondent, the support was a serious burden to the respondent (%)	53.3	28.0	69.5	51.0+

Statistically adjusted results represent mean predicted probabilities based on logistic regression controlling for source of data (SEC or supplemental sample).

Significance levels (two-tailed tests): +=.10; * =.05; **=.01; ***=.001; n.s.=not significant at .10 level; n.a.=not applicable.

Taking on the responsibility for raising grandchildren left behind because of the death of an adult son or daughter can potentially have substantial long-term implications for the grandparents regardless of the cause of death that leads to orphanhood. Table 4 provides some indications of the extent that parents of adult children who die take responsibility for orphaned grandchildren. Note that we use the term orphan to refer to the loss of either parent. Orphans with a remaining surviving parent will have less need to be fostered by grandparents than those who do not (Knodel & Saengtienchai 2004). We cannot distinguish, however, between double orphans (i.e. those whose both parents are dead) from those who still have one surviving parent since information is not available in our survey about whether or not the spouse of the person who died is alive. Related to this limitation of our data is that some orphans who are not being fostered by their grandparents at one point in time may live with them later. This is especially likely in cases of AIDS orphans since some currently surviving parents who are caring for them may be HIV

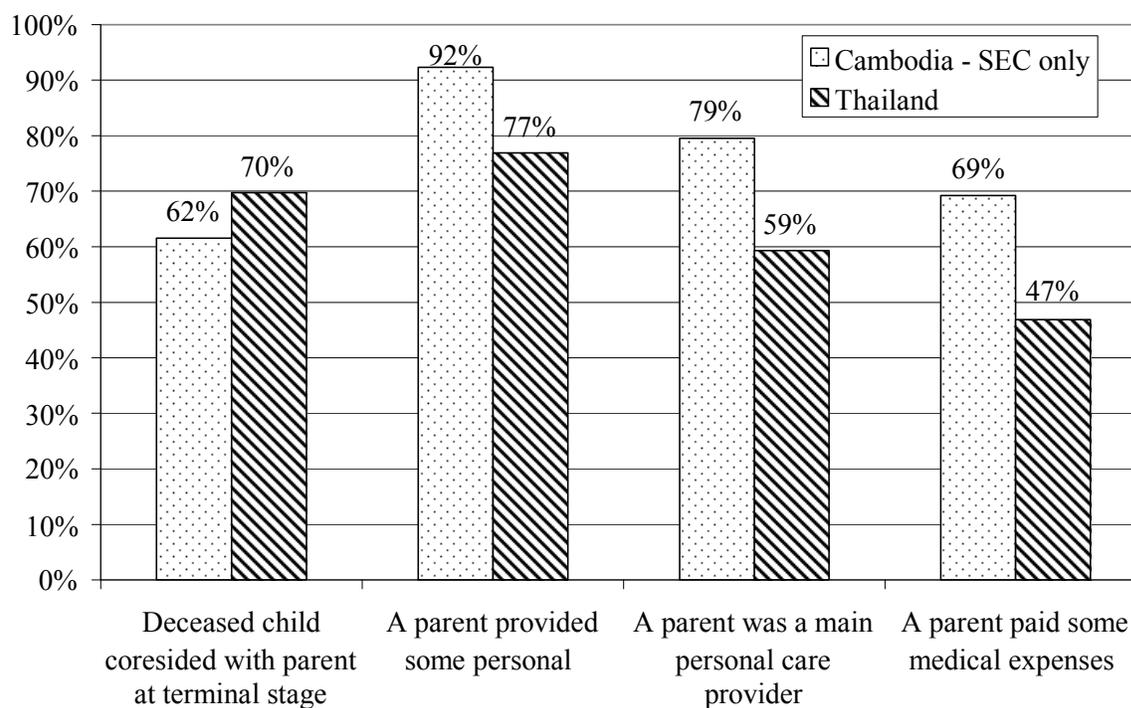
positive and die before the child grows up. Note also that some of the measures shown in table 4 are conditioned on the existence of an orphaned grandchild or on supporting one. This reduces the number of cases available for analysis, which becomes particularly small when results are restricted to the SEC sample.

In considering the potential impact of orphans on older age grandparents in general, it is important to recognize that not all deceased adult sons or daughters had surviving dependent children of their own. As the results indicate, although more than half of the adult children who died left behind one or more minor children (under age 16), at least two-fifths did not have any. There is little difference in this respect between cases involving an AIDS and a non-AIDS death. Among cases in which a minor grandchild was orphaned, a substantial share had spent at least some time living with the bereaved grandparents. Such situations, however, appear to be more common when the cause of death was AIDS than some other cause. Similarly, a substantial share of bereaved grandparents provided some support in cases where a grandchild was orphaned. This also appears to be more common when the cause of death was AIDS. Given that HIV can be passed from one spouse to the other, a possible reason for the greater likelihood of grandparent fostering in cases of AIDS deaths may be that AIDS orphans are more likely to have both parents die than are children orphaned due to death from another cause. Given the lack of information about their survival of the other parent, however, we cannot verify that this.

In the surveys we asked respondents who had supported an orphaned grandchild following the death of the parent to what extent the support presented a burden for them. Respondents whose child died of AIDS were more likely to indicate that the grandchild support imposed a serious burden than those whose child had died from another cause. This does not appear to be a result of prior differences in the extent of poverty between these two groups since they are quite similar with respect to their non-liquid assets scores. While no direct evidence is available from the survey to indicate why this should be so, it is possible that raising an AIDS orphan entails additional difficulties including the possibility that the child may be HIV positive and have more than usual health problems.

Comparison with Thailand. Figure 1 compares Cambodia and Thailand with respect to parental involvement in living arrangements, caregiving and expenses associated with the death of an adult child to AIDS. The Thai data were collected using a different methodology although one that should yield relatively unbiased estimates (Knodel, VanLandingham, Saengtienchai, & Im-Em 2001). For Cambodia, only estimates based on the original SEC are shown to avoid biases associated with the supplemental sample. Given the small number of cases on which the Cambodian information is based and the different data collection methodologies and sampling strategies involved, comparisons between Cambodia and Thailand are only suggestive.

Figure 1. Parental coresidence, caregiving and expenses for an adult child who died of AIDS, Cambodia 2004 and Thailand 1998-99



As figure 1 indicates, Thai parents are commonly involved in the living and caregiving arrangements for their fatally ill children with AIDS as are their Cambodian counterparts. Coresidence at the terminal stage of illness is modestly higher in Thailand than in Cambodia while parental caregiving is somewhat more common in Cambodia. Over 90 percent of Cambodian parents who lost a child to AIDS compared to under 80 percent of Thai parents reported that a parent provided some personal care. More striking is the contrast between Cambodian and Thai parents with respect to main personal caregiving, with almost four-fifths of Cambodian parents saying they did so compared to three fifths of Thai parents. Cambodian parents were also more likely than Thai parents to indicate they paid some medical expenses. This could reflect the almost total absence in Cambodia of government health insurance in contrast to its widespread availability in Thailand (Knodel & Saengtienchai 2005).

AIDS Caregiving. Table 5 provides a number of indicators of living arrangements prior to the death of the person with AIDS and parental caregiving for AIDS parents in Cambodia based on the combined SEC and supplemental samples. For most of the measures shown, only modest differences are evident between urban and rural, married and unmarried, and poor and non-poor parents. For each category shown it was very common for the deceased child to be reported as living with parents. Likewise providing care, both personal and instrumental, was extremely common for all parental groupings being considered.

Table 5. Living arrangements and parental caregiving, combined 2004 SEC sample and 2005 supplemental sample, cases involving an AIDS death

	All AIDS deaths	Location		Marital status		Poverty status	
		Urban	Rural	Married	Non-married	Non-poor	Poor
Base N of cases	118	46	72	53	65	58	60
The deceased child coresided with parent at time of death (%)	78.0	80.4	76.4	75.5	80.0	75.9	80.0
A parent provided some personal or instrumental care to deceased child (%)	95.8	100.0	93.1+	100.0	92.3*	98.3	93.3
A parent was a main personal caregiver to deceased child (%)	90.7	95.7	87.5	98.1	84.6*	94.8	86.7
A parent was a main instrumental caregiver to deceased child (%)	82.2	82.6	81.9	88.7	76.9+	82.8	81.7
Among caregiving cases, months of care provided (mean)	7.4	7.0	7.7	5.8	8.9+	6.2	8.6
Among caregiving cases, caregiving interfered with economic activity (%)	58.4	54.3	61.2	54.7	61.7	57.9	58.9
Among caregiving cases, caregiving interfered with social activity (%)	55.8	50.0	59.7	58.5	53.3	50.9	60.7

Significance levels (two-tailed tests): +=.10; * =.05; **=.01; ***=.001; n.s.=not significant at .10 level

Some difference is evident with respect to the mean number of months of caregiving among parents who provided at least some care. Overall, if parental caregiving occurred, it lasted on average between seven and eight months, ranging from just under six months for married parents up to almost nine months for non-married parents. This is longer than the mean of almost five months reported by Thai parents who provided care to their adult children who died of AIDS.¹⁵ Caregiving can divert time away from income generating activities, thus impacting financial well-being. For more than half of the cases in which parental care was given, it interfered with economic activity thus entailing opportunity costs. How much of a hardship this imposed on parents is unknown but presumably it varied with the duration of caregiving. Approximately similar proportions of respondents reported that caregiving interfered with social activities. Interference with economic and social activity does not appear to vary much by the characteristics of the parent shown in the table.

Direct expenses. Table 6 examines payment of expenses by the parents for their adult children who died of AIDS based on the combined SEC and supplemental survey. The large majority of parents contributed to both medical and funeral expenses regardless of whether they lived in rural or urban areas and regardless of their marital or poverty status. Rural parents and those who were not currently married were somewhat less likely to be the primary source of medical expenses than their urban or married counterparts. Respondents who paid for medical or funeral expenses were asked to what extent the expenses were a burden. Substantial majorities indicated that each of the two types of expense was a serious burden on them. This differs little by location and poverty status, but married individuals were more prone than unmarried to report expenses as a serious burden.

Table 6. Payment of expenses for deceased adult child, combined 2004 SEC sample and 2005 supplemental sample, cases involving an AIDS death

	All AIDS deaths	Location		Marital status		Poverty status	
		Urban	Rural	Married	Non-married	Non-poor	Poor
Parent paid some medical expenses (%)	78.8	82.6	76.4	88.7	70.8*	79.3	78.3
Parent was primary source of medical expenses payments (%)	61.9	71.7	55.6+	75.5	50.8**	58.6	65.0
Parent had net funeral expenses (%)	79.7	84.8	76.4	90.6	70.8**	75.9	83.3
Parent paid medical and/or funeral expenses (%)	86.4	89.1	84.7	94.3	80.0*	86.2	86.7
Among cases who paid, medical expenses were a serious burden (%)	65.6	71.1	61.8	74.5	56.5+	63.0	68.1
Among cases who paid, funeral expenses were a serious burden (%)	74.5	79.5	70.9	77.1	71.7	79.6	70.0
Among cases who paid, medical and/or funeral expenses were a serious burden (%)	74.5	78.1	72.1	80.0	69.2	76.0	73.1

Notes: for base number of cases before selections, see table 5

Significance levels (two-tailed tests): +=.10; * =.05; **=.01; ***=.001; n.s.=not significant at .10 level

As noted earlier, Cambodia is a poor country and poverty is widespread. The extensive level of poverty may mean that most individuals, even if not categorized as poor in Table 6, have few economic resources, and thus paying expenses associated with an AIDS illness was felt as a burden by both those categorized as poor and non-poor. In addition, the percentage of AIDS parents in Cambodia who reported that expenses for their child with AIDS was a serious burden is substantially higher than reported by Thai AIDS parents (Knodel, Im-em, Saengtienchai, VanLandingham, & Kespichayawattana 2002). This too may reflect the more widespread poverty prevailing in Cambodia and consequently the greater hardships that older adults there encounter when faced with the expenses of caring for a child inflicted with AIDS.

Given the unanticipated costs of care, treatment and funerals, AIDS parents may be unable to cover these expenses from cash in hand or savings. As table 7 shows, about a fourth of respondents reported that their ill adult child or family received some assistance from formal sources such as welfare payments by the government, NGO assistance, or help from the community. NGOs were by far the most common source of assistance regardless of location, marital status or poverty status. As noted above, this likely reflects the partnership role of NGOs in Home Based Care with the Government with funding from international aid agencies (Buehler 2006; UNDP 2006; USAID 2003). Government assistance is more commonly reported in urban than rural areas while the opposite is true for community sources. The overall percentage receiving any formal support does not vary much by location or marital status. However, those who were in poor economic situations were less likely than others to receive assistance regardless of which source is considered. This may reflect a more limited knowledge on the part of the impoverished compared to those who are better off about available sources of assistance. The poor may also have less access to formal sources because they lack social capital in terms of connections with influential persons who determine the distribution of such assistance. We note that the current situation may well differ given the rapid expansion of services since the time when the grown children of the respondents died.

Table 7. Means of meeting expenses associated with the illness and death of an adult child, combined 2004 SEC sample and 2005 supplemental sample, cases involving an AIDS death

	All AIDS deaths	Location		Marital status		Poverty status	
		Urban	Rural	Married	Non-married	Non-poor	Poor
Adult child or family received assistance from a formal source during illness or injury (%)	25.4	21.7	27.8	28.3	23.1	32.8	18.3+
Any source (a)	6.8	10.9	4.2	7.5	6.2	8.6	5.0
Government	16.9	15.2	18.1	15.1	18.5	22.4	11.7
NGO	5.9	2.1	8.3	5.7	6.2	6.9	5.0
Community							
<i>Among cases who helped pay medical and/or funeral expenses</i>							
N of cases	102	41	61	50	52	50	52
A parent borrowed money (%)	65.7	63.4	67.2	74.0	57.7+	60.0	71.2
A parent is still in debt (i.e. still owes most of what was borrowed) (%)	40.2	41.5	39.3	36.0	44.2	36.0	44.2
A parent sold land, livestock or household possessions (%)	51.0	26.8	67.2***	56.0	46.2	40.0	61.5*
A parent sold gold or jewelry (%)	24.5	31.7	19.7	20.0	28.8.7	36.0	13.5**

Notes: for base number of cases before selection, see table 5.

(a) Includes from government, NGO, community and a small number who received insurance payments
Significance levels (two-tailed tests): +=.10; * =.05; **=.01; ***=.001; n.s.=not significant at .10 level

Table 7 also indicates several potential means of meeting expenses among those who paid either medical or funeral costs. The most common was to borrow money regardless of location, marital status or poverty status. Among all groups, the majority had gone into debt. Moreover, many of those who borrowed money were still in debt for most of the amount borrowed. Thus overall, two thirds of those who had expenses had borrowed money to cover expenses and two fifths still had most of the debts still outstanding. The second most common strategy to meet expenses was to sell land, livestock, or household possessions. Just over half of the parents who had incurred expenses did so. This was far more common among persons in rural areas than those in Phnom Penh and also far more common among the poor than non-poor. About a fourth of parents who incurred expenses sold some gold or jewelry to raise money. One likely reason why this is less common than other means is that the sample is generally poor and thus many likely had no jewelry or gold to sell.

Loss of filial support. As noted earlier, receiving assistance from children is an essential way in which the physical and material needs of elderly Cambodians are met. Thus the death of a child may threaten the well-being of an older adult. Table 8 examines the extent to which the death of a child to AIDS resulted in the loss of some form of assistance. In over half of the cases, respondents reported that the deceased child had been providing material support for the parental household. An even higher percentage reported that the deceased child had been assisting with chores within the household. Perhaps most seriously, in over two fifths of the cases, the respondent reported that the deceased child was a main source of material support. Differences with respect to the location and marital status of the respondent are not striking in

these respects but poorer parents were particularly likely to have been receiving material support from the deceased child and fully half of them had also indicated that the child was a main source of their material support. A similar association between the loss of main support and poverty was found among AIDS parents in Thailand (Knodel & Im-Em 2004).

Table 8. Loss of support associated with the death of an adult child, combined 2004 SEC sample and 2005 supplemental sample, cases involving an AIDS death

	All AIDS deaths	Location		Marital status		Poverty status	
		Urban	Rural	Married	Non-married	Non-poor	Poor
Deceased child provided support for parental household (%)	52.5	52.2	52.8	50.9	53.9	43.1	61.7*
Deceased child was main supporter of parental household (%)	42.4	43.5	41.7	39.6	44.6	31.0	53.3*
Deceased child helped in chores in parental household (%)	56.8	63.0	52.8	58.5	55.4	58.6	55.0
Among those whose deceased child provided support, loss of support created much difficulty (%)	64.5	75.0	57.9	66.7	62.9	60.0	67.6
Among those whose deceased child helped in household chores, loss of help created much difficulty (%)	59.7	55.2	63.2	51.6	66.7	50.0	69.7

Note: for base number of cases before selections, see table 5.

Significance levels (two-tailed tests): +=.10; * =.05; **=.01; ***=.001; n.s.=not significant at .10 level

Respondents who reported that their child who died had either provided material support or had helped with household chores, were asked to what extent these losses created difficulty for them. Results are also included in table 8. Among AIDS parents, almost two thirds indicated that the loss of the material support created much difficulty and three fifths reported that the loss of assistance with household chores likewise created considerable difficulty. Some differences with respect to place of residence and marital and poverty status are evident although none achieve statistical significance. Similar to findings from Thailand, the poor were more likely to report that the loss of material support created severe difficulty (Knodel & Im-Em 2004).

Community reaction. AIDS is commonly portrayed as 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. Stigma may extend beyond the person who is infected to family members including parents, especially if they are co-resident or involved in caregiving. Research in Thailand found that community reaction is considerably more positive than typically portrayed in the general discourse about the AIDS epidemic (VanLandingham, Im-em, & Saengtienchai 2005). In order to judge the community reaction that AIDS parents experienced, we included questions about both potential positive and negative reactions. With respect to positive reactions, we asked whether or not neighbors visited, helped look after the sick child, brought food or medicine, or helped with hospital visits. With respect to

negative reactions, we asked if neighbors avoided talking to the respondent or other household members, gossiped, or avoided visiting. Results are presented in table 9.

Table 9. Community reaction to the illness and death of an adult child, combined 2004 SEC sample and 2005 supplemental sample, cases involving an AIDS death

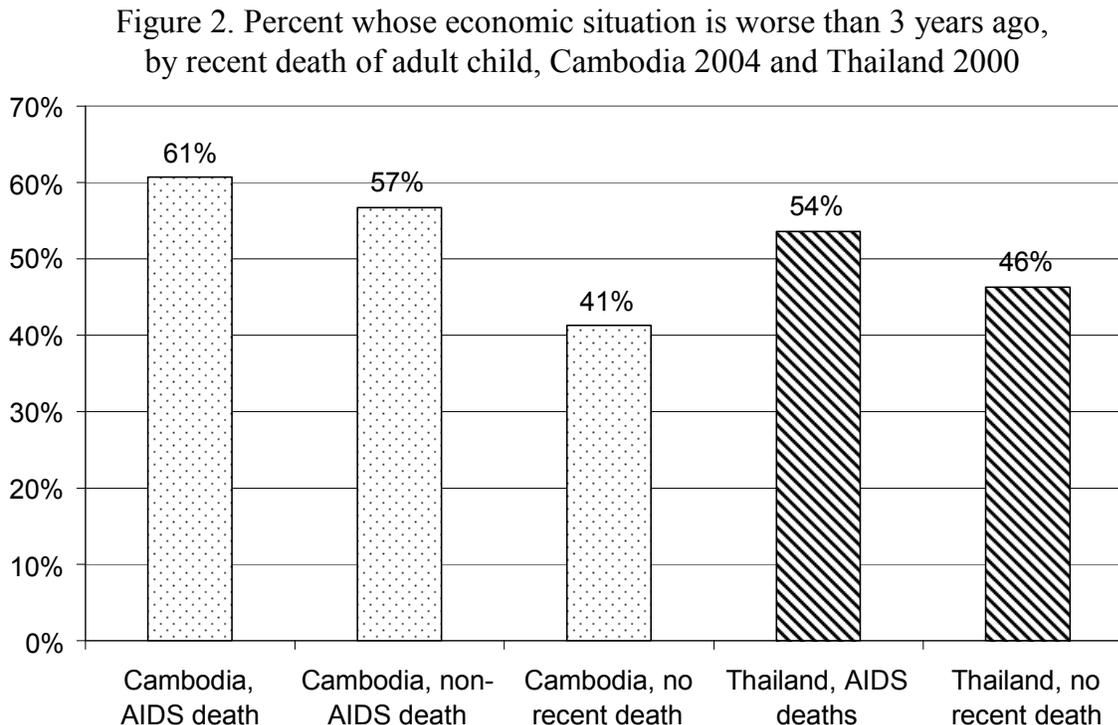
	All AIDS deaths	Location		Marital status		Poverty status	
		Urban	Rural	Married	Non-married	Non-poor	Poor
Positive reactions							
Neighbors visited (%)	96.6	95.7	97.2	98.1	95.4	94.8	98.3
Neighbors looked after sick child (%)	33.1	43.5	26.4+	45.3	23.1**	31.0	35.0
Neighbors brought food or medicine (%)	48.3	43.5	51.4	54.7	43.1	46.6	50.0
Neighbors helped with hospital visits (%)	27.1	39.1	19.4*	28.3	26.2	31.0	23.3
Any positive reaction (%)	96.6	95.7	97.2	98.1	95.4	94.8	98.3
Number of positive reactions (mean)	2.1	2.2	1.9	2.3	1.9+	2.0	2.1
Negative reactions							
Neighbors avoided talking to parents or other household members (%)	16.1	15.2	16.7	15.1	16.9	15.5	16.7
Neighbors gossiped (%)	21.2	17.4	23.6	18.9	23.1	22.4	20.0
Neighbors avoided visiting (%)	16.9	17.4	16.7	17.0	16.9	17.2	16.7
Any negative reaction (%)	22.0	17.4	25.0	20.8	23.1	24.1	20.0
Number of negative reactions (mean)	0.5	0.5	0.6	0.5	0.6	0.6	0.5

Note: for base number of cases, see table 5.

Significance levels (two-tailed tests): +=.10; * =.05; **=.01; ***=.001; n.s.=not significant at .10 level

As was found in Thailand, parents of those who die of AIDS are considerably more likely to report positive than negative reactions from their neighbors. Overall almost all respondents who lost a child to AIDS reported that neighbors visited and quite a few reported other positive responses with almost half saying that neighbors brought food or medicine. In contrast, far fewer reported any negative reactions. Just under one fourth reported gossip, the most common negative reaction. Less than one in six cases reported that neighbors avoided talking with them or avoided visiting. In general, this pattern of positive and negative reactions differs little by location or marital or poverty status.

Impact on economic well-being. To assess if the death of an adult child due to AIDS as well as due to other causes impacts the parents' economic well-being, we rely on three of the measures discussed earlier as dependent variables: liquid asset score, subjective assessment of economic satisfaction, and subjective assessment of economic well-being compared to three years ago. We hypothesize that there are negative economic consequences to experiencing the death of a child, and that they are stronger in the case of AIDS deaths than non-AIDS deaths. In this respect, the third measure is the most straightforward to interpret since it directly refers to change in the respondent's economic situation over time. Figure 2 shows the percent who indicated that their current economic situation was worse than three years earlier according to experience with a recent death of an adult child. Results based on a similar question asked in a survey conducted in Thailand in 2000 that included parents who lost an adult child to AIDS and those who experienced no recent death of an adult are provided for comparison.¹⁶



Both the Cambodian and the Thai results suggest that experiencing the recent death of an adult child worsens the parents' economic situation. Cambodian parents experiencing a recent child death were considerably more likely than others to indicate that their economic situation had become worse, but only a modest difference is evident between those whose child died from AIDS and those whose child died from another cause. Thai parents who lost a child to AIDS were also more likely to report that their economic situation had worsened than those who did not experience any recent adult child death. The impact in Thailand, however, appears to have been less pronounced than in Cambodia, possibly reflecting the generally better economic situation in Thailand and the more extensive formal safety net, especially with respect to government health insurance.

There are several factors that potentially could confound our analysis of the relationship between child death and parental economic well-being and thereby undermine a causal interpretation. Perhaps the most important is the well established relationship, at least for the developed world, between lower economic well-being and higher mortality (Preston & Taubman 1994). Thus a negative association between experiencing an adult child death and parental economic well-being could emerge because low economic well-being led to the death rather than the reverse.¹⁷

To minimize the chance of misinterpreting the cause of an association, we follow several strategies. First, as already noted, our analysis includes a measure of economic well-being compared to three years ago. If a death adversely influences economic well-being, respondents should report a worsening in economic well-being over time. There is little reason to expect an individual who loses a child will report

deteriorating economic well-being if the association is solely in the opposite direction (i.e. because their low prior economic well being led to the death).

Second, we statistically adjust results for the respondent's economic standing prior to the death event using three measures. The first is education, which is determined early in life, and as our data reveal is strongly associated with economic well-being. The second is place of residence, which is also relatively fixed for this sample for the period between onset of the child's illness and the time of interview.¹⁸ The third measure is the non-liquid assets score described earlier. Results are additionally adjusted for gender and marital status of respondent. Descriptive statistics and the coding scheme for all of the control variables are provided in Appendix B.

Table 10: Adjusted and unadjusted economic well-being scores

	Unadjusted	Adjusted ^a
Liquid asset score		
Grand mean	50.3	50.3
Mean if....		
No children died	51.0	50.9
Child died due to non-AIDS cause	47.4	47.0
Child died due to AIDS	45.4	46.6
F-Value	2.64*	2.57*
Subjective economic well-being score		
Grand mean	1.97	1.97
Mean if....		
No children died	2.00	2.00
Child died due to non-AIDS cause	1.89	1.89
Child died due to AIDS	1.79	1.80
F-Value	4.67**	3.96**
Economic well-being change score (during prior three years)		
Grand mean	1.71	1.71
Mean if....		
No children died	1.75	1.75
Child died due to non-AIDS cause	1.56	1.55
Child died due to AIDS	1.53	1.48
F-Value	4.77**	6.52**

p < .05 * p < .01, ** p < .001, one-tailed test

a Adjusted scores are calculated using analysis of variance and control for age, fixed asset score, sex, place of residence, education and marital status.

In our multivariate analysis, each of our three measures of economic well being is treated as continuous with higher scores indicating more favorable situations. Table 10 examines mean well-being scores across children's death status. Both unadjusted and statistically adjusted results are included. Adjustment was done using an analysis of variance procedure. Our hypotheses are confirmed for each of the individual scores. Each displays a negative association with child deaths, and each association is statistically significant. Thus, experiencing a death is associated with lower economic well-being. In addition, the

relationship is robust whether or not adjustments are made for possible confounding influences, suggesting that the association runs causally from death to economic well-being. The strongest association exists with the measure 'well-being compared to three years ago'. Adjusted results show that the score is highest for those without a child death, much lower for those with a non-AIDS death and lower still for those with an AIDS death.

Table 11 shows standardized beta coefficients that result from ordinary least squares regressions that predict the three well-being scores, unadjusted and then adjusted for other covariates.¹⁹ Since these are standardized results, they can be compared for strength of association across the well-being scores. For the adjusted results, an AIDS death is most strongly associated with the change in well-being measure, although the association with economic satisfaction is nearly as strong. These coefficients confirm that an AIDS related adult death is likely to have adverse economic consequences for the older-aged parents of the person that died. Experiencing an AIDS death is strongly associated with lower economic well-being, when comparing this group to those not experiencing a child death. Non-AIDS deaths also appear to have negative consequences on economic well-being, but overall the impact does not seem to be as quite as strong as for an AIDS death.

Table 11: Standardized regression coefficients for economic well-being scores

	Unadjusted	Adjusted ^b
Liquid asset score ^a		
beta for non-AIDS death	-0.033	-0.034*
beta for AIDS death	-0.056*	-0.044*
Economic satisfaction score ^a		
beta for non-AIDS death	-0.038	-0.036
beta for AIDS death	-0.078**	-0.074**
Well-being compared to three years ago score ^a		
beta for non-AIDS death	-0.055*	-0.058*
beta for AIDS death	-0.069**	-0.087**

* $p < .05$ ** $p < .01$, one-tailed test

^a Comparison category is no death

^b Adjusted scores control for age, fixed asset score, sex, place of residence, education and marital status

Conclusion

Several major findings emerge from this first study of the impact of the AIDS epidemic on older persons in Cambodia based on systematically collected quantitative evidence. Undoubtedly the most important is the major role that older aged parents play in providing living quarters, caregiving, and paying expenses for adult sons and daughters who become ill and die of the disease. Based on the unbiased estimates of the original SEC sample, over 60% had their child living with them at the terminal stage of illness, over 90% had provided some personal care, almost four fifths had provided main personal care, and over two thirds had helped pay for medical expenses. These findings are quite consistent with earlier research in Thailand that also revealed high levels of involvement among Thai parents of adult children who die of AIDS. That an even higher percentage of Cambodians than Thai parents provide care and pay expenses may simply underscore the even greater lack of alternatives to parental assistance and the more extensive poverty in

Cambodia than in Thailand. Unfortunately this major contribution of older persons to the care and expenses of adults with AIDS in Cambodia, as in much of the rest of the world, is largely unrecognized. As a result, no programs are designed to assist these elders in their home care activities by providing knowledge, financial help, psychological support, or respite care relief. Moreover, only a fourth report that their ill child received any assistance from a formal sources, most of which was provided by NGOs rather than the government or community. This is quite in contrast to the situation in neighboring Thailand, where the government is a main provider of health insurance and to a lesser extent welfare payments to persons with AIDS or their families and where NGOs play a much less significant role (Knodel & Saengtienchai 2005). The weak government role in providing formal support to persons with AIDS or their families reflects the general underdevelopment of public services in Cambodia (Coates 2005). The formal assistance that is provided does not appear well targeted in as much as, regardless of source, the poor are less likely than those better off to receive it.

Older adults receive somewhat broader recognition with respect to care for AIDS orphans. As in Thailand, however, a substantial share of adult Cambodians who die of AIDS do not leave dependent children behind, in part because many who die have not been married. Among those who do leave dependent children behind, grandparents often play an important role in taking care of the orphans. Nevertheless, caring for ill adult children and assisting with their expenses is considerably more widespread among older persons than is fostering grandchildren, despite a far lower recognition of this contribution.

While older persons make important contributions to how Cambodian society is coping with the AIDS epidemic, this comes at considerable cost to them. Besides direct expenses, a substantial share of AIDS parents in Cambodia interrupt their economic activities as a result of caregiving. In addition, many go into debt and in some cases sell assets to help cover the expenses they incur as a result of their child's illness and death. Given the pervasive poverty in Cambodia, it is not surprising that the majority who do pay medical or funeral expenses, and to a lesser extent to those who help support surviving orphans, report that this creates a serious burden for them. Our multivariate analysis comparing measures of economic well-being among older aged parents who lost a child to AIDS or to other sources with those who have not experienced the recent loss of an adult child strongly suggests negative economic consequences result from the child death, especially if due to AIDS.

On a more positive note, while negative community reactions towards parents of adults with AIDS is not absent in Cambodia, it appears that sympathetic and supportive reactions from neighbors are far more common. Again this echoes findings from neighboring Thailand. The predominance of positive community reaction suggests that programs designed to build on community support to assist families affected by AIDS would meet with less resistance than might be assumed otherwise. The apparent relative community tolerance of parental caregiving and assistance to HIV infected adult sons and daughters may also contribute to the high levels of home care provided by parents.

Clearly a society's culture, politics and level of socioeconomic development as well as the epidemiology of the epidemic itself will condition the impact AIDS has on older persons. The many similarities

between Cambodia and Thailand may reflect their relatively similar cultural backgrounds, rooted in Theravada Buddhism. Nevertheless there is considerable emerging evidence from elsewhere in the world that older aged parents play important roles in caring for their adult children and at the same time are adversely impacted by the illness and death of a son and daughter due to AIDS (Knodel & VanLandingham 2002). Moreover situations can change over time. The role of parents as caregivers and providers of support is likely to be very substantially affected by the major changes in care and treatment programs taking pace in Cambodia and elsewhere and particularly by the expanded access to effective anti-retroviral therapy. Clearly additional systematic documentation of the situation of older persons in relation to the epidemic and particularly in their role as parents of those who become infected and die is needed. And even more importantly greater recognition of this role and its consequences by those in charge of programs to deal with the epidemic is long overdue.

Endnotes

¹ A complete list of reports and publications of the Thai research is available at <http://aidseld.psc.isr.umich.edu/>.

² Although parents are most likely to suffer adverse consequences, we note that other older generation relatives, such as grandparents or siblings of parents, could experience some of these same consequences.

³ The age limit of parents who recently lost an adult child was lowered to 50 for the supplemental survey to facilitate finding eligible cases. Although the SEC sample is representative if properly weighted, applying weights is not appropriate once the SEC and supplemental samples are combined as they are for most analyses in the present study. Thus all results are based on unweighted data.

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⁵ Suspected AIDS deaths were determined as follows, with the number of cases in parentheses: died of TB (10), shingles with severe weight loss (1); severe weight loss and at least two of four additional AIDS symptoms (13), moderate weight loss and at least three of four additional AIDS symptoms (4). The four AIDS symptoms were diarrhea, cough, fever, and headache lasting 4 weeks or longer.

⁶ For example, while the proportion of parents who helped pay for medical costs is likely overstated in the supplemental sample, there is no obvious reasons why the proportion who found it a burden to pay among those who paid would be biased.

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⁹ Toilet and flooring types are each coded on a five-point scale while type of roof is coded on a three-point scale. For example, having no toilet facility is given a score of 1 and having a flush toilet connected to a sewer with a septic tank is given a score of 5. A rudimentary floor (e.g. earth) receives a lower score than a more modern floor, and a rudimentary roof (e.g. thatch) receives a lower score than a more modern roof.

¹⁰ The percentiles were calculated based on all respondents in the combined SEC and supplemental sample and thus do not necessarily have a mean of 50 for the sub-sample of respondents who experienced a recent adult child death.

¹¹ Both of these items appear to be unaffected by interviewer effects.

¹² In subsequent tables, urban refers to respondents living in Phnom Penh province including both central Phnom Penh and the peri-urban periphery. Rural refers to all other respondents since none of the provincial urban sites were officially classified as urban.

¹³ In this and subsequent tables, the indicators of statistical significance are provided only as a rough guide to help judge the strength of differences found between categories given the nature of the sampling.

¹⁴ For the large majority of outcomes, this has the effect of reducing the extent of differences compared to unadjusted results (which are not shown).

¹⁵ Original calculation from a 2000 survey of AIDS parents in Thailand (Knodel et al. 2002).

¹⁶ For a description of the survey see Knodel et al. 2002.

¹⁷ Although we are concerned with the economic well being of the parents rather than of the deceased child, the two are likely highly correlated.

¹⁸ For the purpose of this analysis, we distinguish three residential categories (central districts of Phnom Penh province, the remaining peri-urban areas of Phnom Penh province and rural areas outside Phnom Penh). Central Phnom Penh respondents score higher on economic well-being than do those in the peri-urban areas, who in turn have higher economic standing than those in rural areas of other provinces.

¹⁹ Regression results for the covariates are provided in Appendix C. In general they conform to expectations. Those with higher education, those living in Phnom Penh, and those with greater fixed assets, are more likely to have higher economic well-being than others.

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Appendix A. Relation of asset indices to adult death event

Table A-1: Mean scores for individual liquid and fixed assets by death of children status

	No deaths	Non-AIDS death	AIDS death	P-Value ^a
<i>Individual liquid assets</i>				
Radio	.742	.684	.669	.07
Television	.698	.673	.686	.43
Motorcycle	.383	.347	.322	.18
Jewelry	.328	.276	.195	.00
Automobile	.068	.041	.034	.11
<i>Individual fixed assets</i>				
Toilet	2.59	2.70	2.60	.33
Roof	2.30	2.24	2.25	.29
Floor	2.30	2.24	2.18	.41

a One-tailed, determined by F-Ratio test

Table A-1 displays means scores by death of children for the five liquid assets and three fixed assets discussed in the main text. Since the liquid assets are coded 0 and 1, the mean simply represents the proportion owning the amenity. It is clear that each of the liquid assets are more likely to be present in households where there has been no death, and least likely to be present in households where there has been an AIDS death. Jewelry is most strongly related to a death and radio moderately related. Other items do not show strong associations but run in the expected direction. Fixed asset scores vary little by death and there is no consistency in the direction of association. While a composite measure of liquid assets is highly related to child deaths, a composite of fixed assets displays virtually no correlation.

Appendix B. Descriptive statistics for control variables Introduced in the Analysis of Impact of an Adult Child Death on Material Well-being

Table B-1: Descriptive statistics for control variables by death of children status

	Total	No deaths	Non-AIDS death	AIDS death	P-Value ^a
N of cases	1376	1160	98	118	--
Mean age	67.9	68.3	68.2	63.0	.00 ^a
Mean fixed asset score	50.0	50.1	50.3	49.0	.46 ^a
Gender (% distribution)					
Female	64.2	62.8	68.4	73.7	
Male	35.8	37.2	31.6	26.3	.04 ^b
Residence (% distribution)					
Urban Phnom Penh	21.2	20.8	22.4	24.6	
Phnom Penh periphery	16.9	17.1	17.3	14.4	
Rural	61.9	62.2	60.2	61.0	.85 ^b
Education (% distribution)					
No education	55.8	55.7	62.2	51.7	
Incomplete primary or pagoda	27.5	27.4	20.4	33.9	
Complete primary	6.2	5.8	6.1	10.2	
Secondary and beyond	10.5	11.1	11.2	4.2	.05 ^b
Marital status (% distribution)					
Married	59.5	59.7	63.3	55.1	
Not married	40.5	40.3	36.7	44.9	.46 ^b

a Determined by F-Ratio test

b Determined by χ^2 test

Table B-1 summarizes descriptive statistics for the variables introduced as control in the analysis of impact of a adult child death on material well-being. Note these refer to the combined original SEC and the supplemental samples. The overall mean age of the sample is about 68 years. About 2/3 of the sample are female, and a little less than 2/3 live in rural areas. About half of the sample has no education and about 10% have secondary and beyond. About 60% of the sample is married. Age, sex and education show significant associations with death of children status, while fixed asset score, place of residence and marital status is unrelated.

Appendix C: Complete regression results predicting economic well-being scores

Table C-1. Complete regression results predicting economic well-being scores

	Liquid asset score		Subjective well-being score		Well-being compared to three years ago score	
	Adj.	Unadj.	Adj.	Unadj.	Adj.	Unadj.
No deaths	comp	comp	comp	comp	comp	comp
Non-AIDS	-3.45**	-3.36	-0.11	-0.11	-0.20*	-0.19*
AIDS	-4.32**	-5.39*	-0.20**	-0.21**	-0.27**	-0.22**
Age	-0.02		+0.00		-0.01*	
Male, married	comp		comp		comp	
Male, not married	-3.17		+0.06		+0.00	
Female, married	-2.35		+0.18*		+0.06	
Female, not married	-2.62		+0.14*		+0.24**	
No education	comp		comp		comp	
Incomplete primary/pagoda	+1.30		+0.11		+0.09	
Complete primary	+5.03*		+0.20		+0.13	
Secondary +	+11.42**		+0.16		+0.01	
Rural	comp		comp		comp	
Urban Phnom Penh	+6.60**		-0.29**		-0.02	
Phnom Penh periphery	+5.88**		-0.71*		-.012	
Fixed asset score	+0.595**		+0.005**		+0.006**	
Constant	19.82	50.74	1.40	2.00	1.84	1.75
R-Sq.	.51	.00	.04	.01	.05	.01
F	117.5**	2.3	4.8**	4.6**	6.3**	4.8**

* $p < .05$ ** $p < .01$, one-tailed test for children death status, two-tailed test for other covariate

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