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**Health Impacts of Co-residence with and Caregiving to Persons with HIV/AIDS
on Older Parents in Thailand**

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Abstract

An emerging literature indicates that parents are main caregivers to persons with HIV and AIDS (PHAs) in Thailand, especially during the late stages of illness. Very little research has examined whether and to what extent this caregiving role affects the physical and psychological health of older persons who give such care, especially in Thailand and other developing countries, where most infections occur. This paper explores these potential health impacts of caregiving for 394 households having older parents who had a child die of AIDS versus 376 households with older persons who did not, based upon original survey data collected during 2000 in three provinces (from 3 sub-regions) in Thailand. We supplement these survey data with qualitative data resulting from 18 in-depth interviews of older persons who had lost an adult child to AIDS.

We find that large proportions of older persons with PHA children provide a variety of time consuming and strenuous caregiving services to them. Mothers shoulder most of this burden. Mothers who have had a child die from AIDS reported lower levels of overall happiness than mothers who did not. Mothers and fathers of PHAs who died report lower levels of overall happiness now compared to 3 years ago (before the time of the death of their child) with respect to parents from households that did not experience an adult child death. Many AIDS parents experienced anxiety, insomnia, fatigue, muscle strain, and head and stomach aches during the time they cared for their ill children, and many experienced these problems often.

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INTRODUCTION

Thailand has faced over the past decade a moderately severe HIV/AIDS epidemic, with adult prevalence currently around 2%. While incidence has declined sharply over the past several years, there remains a large number of persons currently infected, approximately 750,000 at the end of 1999 (UNAIDS 2000). That these young adults infected with HIV have children is widely recognized, but the fact that they have parents as well is often ignored. AIDS has made the loss of young adult children to older adults a much more common event than it was previously. Between eight and thirteen percent of an older age cohort in Thailand (those age 50 and above in 1995) will experience the death of an adult child to AIDS before their own death (Wachter et al. 2002; Wachter et al. in press). Unlike deaths to young adults that occur suddenly, like those due to accidents or violence, persons living with HIV/AIDS (PHAs) often require substantial care and other resources as they become ill.

The economic, social, and familial context in which this caregiving occurs is vastly different from the situation in the developed world. In the United States and Canada, for example, effective antiviral and opportunistic treatments are available to most PHAs through well-funded health care and research institutions. Many PHAs remain healthy under these treatments, thus avoiding the need for intensive caregiving. For PHAs who do become very ill, institutionalized care is widely available; use of unpaid home care was reported by only 14% of a nationally representative sample of American PHAs (London et al. 2001). Where informal caregiving does occur, the majority of caregivers are young adults - gay and bisexual men in particular. Friends are more likely to be called upon to provide care than are family members (Turner et al. 1994; Johnston et al. 1995)

Even in such an environment where health care is provided to PHAs by nonprofessionals infrequently, and is provided by young adults where it does occur, caregiving has been found to exact a toll on the health of nonprofessional caregivers. Several studies have documented elevated rates of depression and anxiety, and increased vulnerability to physical symptoms such as fatigue and insomnia among lay caregivers to PHAs in the North American context (Lippmann, James, and Frierson 1993; Stetz and Brown 1997; Pearlin, Aneshensel, and LeBlanc 1997; Leblanc, London, and Aneshensel 1997; Herth 1993, Flaskerud and Tabora 1998; and Joslin and Harrison 1998). Powell-Cope and Brown (1992) report that the 53 caregivers of PHAs (13% of whom were parents) in their U.S. study experienced pervasive stigma resulting from their close association with a PHA.

In Thailand and in other moderate to high prevalence developing countries, the health care and social contexts are vastly different from the North American environment, and these differences have important implications for who gives care and for the associated consequences of caregiving. Specifically, the frequency with which multiple generations live in the same household (Knodel et al. in press), the much higher rates of infection, and the more modest health care budgets in Thailand (World Bank 2000) vis à vis the U.S. lead many ill PHAs to live with their parents and to be cared for by them rather than by health care personnel in institutions. Fully two-thirds of Thai adults who died of AIDS either lived with or adjacent to a parent by the terminal stage of illness; a parent, usually the mother, acted as a main caregiver for about half (Knodel et al. 2001).¹ Receiving both physical and emotional support from family are key reasons Thai PHAs give for wanting to live with their relatives (Juthavigit 1994). Community

¹The family also provides the bulk caregiving for PHAs in many African countries affected by the epidemic. See, for example, Ntozi and Nakayiwa (1999).

reaction to PHAs and their families in Thailand may also be more supportive than in North America, where reports of negative reactions abound. In work related to the research reported here, we find that the majority of Thai families, PHAs, and community observers in our samples report generally neutral or positive community response to families affected by AIDS -- this more positive social environment is likely due at least in part to the fact that the behaviors associated with HIV transmission in Thailand, commercial heterosexual relations, are not themselves stigmatized in the way that behaviors associated with transmission of HIV in the North American context are stigmatized (VanLandingham et al. 2002; Turner et al. 1998). More importantly for the purposes of this paper, this more supportive social environment in Thailand may mitigate some of the strains and associated health problems that caregivers experience elsewhere.

A proposed model of the potential impacts of caregiving on the health of older Thai caregivers is outlined in the figure. Caregiver health, including dimensions of both physical and mental health, may be adversely affected by the strains and worries associated with intensive caregiving to PHAs. As suggested in the far right panel of the figure, strained muscles and exhaustion from lifting, and from being more or less constantly on call, are potential negative health outcomes. Exposure to opportunistic infections, such as TB, results from the close proximity required by caregiving. Mental strains associated with being in close and frequent contact with a loved one in such agony may manifest themselves in sleeplessness and anxiety. Stress and burnout could also affect some caregivers (UNAIDS 2000).²

Caregiver health in this model is affected by caregiving, which typically involves many of the tasks outlined in the middle panel of the figure. Parents may be involved in personal care, instrumental care, or both. Personal care consists of help with activities of daily living (ADL function), including personal care hygiene tasks (help with eating, bathing, dressing, toileting), personal care mobility tasks (helping with the getting in and out of bed, getting around inside house), and home health care (the administration of medications, wound dressing). Instrumental care consists of help with the daily affairs of the patient, e.g., meal preparation, laundry, shopping, transportation, and handling the finances or legal matters for the PHA.

More specific features of care taking will in turn depend upon key elements of the social, cultural, and economic context, some of which are highlighted in the far left panel of the figure. In Thailand, parents living with or close to their adult children is very common (Knodel et al. in press), putting many young adults who become infected with HIV in the same neighborhoods, household compounds, or households as their parents. For adult children who have moved away, return migration among PHAs back to their parental homes is widespread; many in fact return for caregiving (Knodel and VanLandingham in press). Whether or not the adult child has moved away, young adults generally retain very close contact with their parental homes and especially with their parents. Expectations of old age support to parents from adult children in the form of either remittances and/or coresidence are widespread (Pramualratana 1990), and given the strong connections among family generations throughout their lives, parental care taking of children or

² Caregiving is not the only way in which older Thais could be affected by the infection of their young adult children. Expenses for medicines, food, clothing, and transportation may lead to less money being available for the parents' own needs. Time and opportunity costs may also result in economic hardship, worry, and may also cause parents to forego normal social relationships and other leisure activities in their communities. Social alienation could have very negative consequences for a parent's mental health and social relations. See VanLandingham et al. (2000) for a more detailed theoretical discussion of how older parents can be affected by the infection of their adult children with HIV; Knodel et al. (2002a) for an analysis of the economic impacts on parents of having a child die of AIDS; and VanLandingham et al. (2002) for an analysis of community reaction to PHAs and their families.

grandchildren if they should become ill is also common, especially by mothers or grandmothers (Wongsith and Siriboon 1999). Indeed, Muecke (2001) finds that parental and especially women caregivers of PHAs in her study describe such caregiving as their duty.

The mother holds a central place in the Thai *Weltanschauung*. Mother personifies the nurturing force of the Thai universe (Keyes 1989), and epitomizes the pure and the good (*bunkhun*) (Mulder 1990). More practically, daily tasks of cooking and providing personal care for children fall clearly into the feminine domain in Thai household division of labor. Given these gendered dimensions of the cultural context, one would expect that it would be mothers rather than fathers who would provide the bulk of caregiving to adult children should they become ill. Differences on the types and amount of time spent on tasks by the sex of the caregiver are not so clear in the North American context, although women caregivers report more hours of housework for PHAs than do men (Ward and Brown 1994).

The objective of the current paper is to apply the above conceptual framework to an analysis of caregiving to Thai PHAs by their older parents. Because the role of parents is so much more intensive, extensive, and different in the context of many developing country epidemics vis à vis epidemics in developed countries, we explore whether and to what extent the physical and mental health of older AIDS parents may decline from their close involvement with their ill children, relative to parents who do not suffer this unfortunate set of events. We hypothesize that parents who are most closely involved with caregiving will experience the most severe impacts on their health. These negative impacts will result from physical and emotional strains associated with caregiving and will manifest themselves both in lower self-reported levels of overall health, and in a higher frequency of specific symptoms of ill health. Mothers will be more closely connected with the intimate tasks of personal caregiving to PHAs than will fathers, and as a result will suffer more of the negative health consequences of caregiving than fathers will.

METHODS

Identifying AIDS affected households through a national probability sampling of households in Thailand would face a number of formidable obstacles. First, given the low prevalence of AIDS outside of the north, identifying a sufficient number of affected households would require substantial resources. Second, given the sensitive nature of both AIDS and a young adult death in the household, approaching randomly selected households without a large investment in contact procedures would likely result in unacceptably high refusal rates or an unwillingness to identify oneself as a household of interest, i.e., an AIDS affected households. We thus decided to employ a more purposive sampling strategy and to rely heavily upon intermediaries to identify and help us recruit families who would be willing to participate.

To explore the impact of AIDS in a variety of areas, we chose three provinces in distinct settings: Chiang Mai, one of the highest prevalence provinces in the far north; Phichit, a province with low levels of prevalence in the lower north; and Rayong, one of the highest prevalence provinces on the southeast seaboard. Our intermediaries were in most cases local health officials employed at village cluster health stations and/or village health volunteers. Within the selected provinces, we chose village clusters (*tambon*) in which it was known that the local health officials were knowledgeable about their community. In brief, the identification of AIDS affected families occurred as follows. First, the intermediary listed all deaths due to AIDS that had occurred in the community within the past 3 years. This employed the use of death registers where available and memory elsewhere. This was quite straightforward where the case died

locally (these cases are widely known about) but more difficult for cases who died elsewhere. As a result, the list of AIDS parents eligible for interview disproportionately represent those whose deceased son or daughter either lived locally before becoming ill or who became ill elsewhere but returned to the parental community before dying.

Next we identified cases who died between 6 months and 3 years prior to our scheduled interview period. We chose this period to allow enough time for many of the effects of an AIDS death to manifest themselves (which would not be the case for a shorter time frame) and to minimize recall problems (which would be more problematic in a longer timeframe). We also eliminated a small number of cases from consideration for whom the intermediary believed would not agree to an interview. In several Chiang Mai sites, where there were large numbers of affected families, we systematically selected households from our sampling list. In other areas where there were fewer affected families, we selected all of them for interview.

Our intermediaries also prepared a list of control households that had not experienced a young adult death during the time period of interest, matched to our cases by the age, marital status, and socioeconomic status of the parent(s). Intermediaries were instructed to contact the case and control households, to explain the nature of the survey, and to ask permission before the interview team arrived, but in practice the extent to which these instructions were followed varied by location. We do not ask in the interviews about AIDS directly but rather about young adult deaths in the household; we know whether the death was due to AIDS from our community intermediaries. In practice, when asked the cause of death of their deceased son or daughter, in two-thirds of the AIDS parents' interviews the respondent explicitly stated AIDS. A substantial share of those who did not state AIDS as the cause of death still were open about the fact that their child had AIDS but gave as the cause of death some AIDS related symptom or illness (e.g. tuberculosis or fungal infection). Interviews were conducted throughout 2000. Our sample covers 41 different sub-districts (*tambon*) in 14 different districts (*amphoe*) in the 3 provinces listed above.

Characteristics of the sample are presented in Table 1. We conducted a total of 394 interviews with AIDS parents and 376 interviews with qualified non-AIDS parents. The AIDS and non-AIDS parents that we identified for interview could be either a married couple living together or a separated, divorced or widowed parent. Almost two thirds of both AIDS and non-AIDS parent households involved coresident married couples. Most of the remainder (over a fourth) involved widowed, divorced or separated mothers and less than a tenth involved widowed, divorced or separated fathers. In cases of coresident married parents, we permitted both parents to participate in the interview. In cases where both parents were alive and living together, certain items in the questionnaire were asked separately for each parent. Information on spouses of the respondent could be provided directly by the spouse if present or by proxy by the respondent. In this way, the interviews generated information for 649 AIDS parents (363 mothers and 286 fathers) and 621 control parents (345 mothers and 276 fathers). In one sixth of the AIDS parents cases, the parents experienced the loss of more than one adult child within the previous 5 years (with about half also being due to AIDS). In such cases, interviewers were instructed to select the most recent child who died of AIDS, excluding any child whose death occurred less than 6 months earlier, and use that child as the referent for questions about the deceased child.

Refusal Rates and Other Sources of Bias

Response and refusal rates are difficult to calculate with precision since the quality of record keeping by our intermediaries varied by location. For Rayong, which had the most careful records, our refusal rate was about 6%. More details about the survey methodology are available in our survey report available on line (Knodel et al. 2002b).

Since our survey was not conducted on a probability sample of either AIDS or non-AIDS parents, results cannot be generalized to the overall population as could results from a nationally representative sample. At least with respect to age, however, the AIDS parents we interviewed are distributed quite similarly to what we would expect from a representative sample (Knodel et al. 2002b). Despite having the expected age distribution, there is little doubt that our sample of AIDS parents under-represents those whose adult children died away from their parental community. In general, parents whose child died away from their locality are probably less vulnerable to some of the potentially adverse health impacts than those who lived with or nearby the adult child at the terminal stage. Additional potential biases could be present if willingness to be interviewed were related to some of the outcomes under study or if intermediaries had only selective awareness of the AIDS cases who died locally. Table 1 indicates that on most measures our AIDS parents are quite similar to our control parents, although the AIDS parents are slightly older and slightly less well educated than the controls. More detailed comparisons between our case families and controls, and between our case families and national data can be found in our project report (Knodel et al. 2002b).

Key findings from these survey data are supplemented with interview data we collected from 18 interviews of parents who lost and, in most cases, provided care to an adult child who died of AIDS. These interviews cover a broad range of issues related to the consequences for older persons of having a family member die of AIDS. These interviews took place between mid-1998 and mid-1999 in Bangkok, and in Chiang Mai, Rayong, and Petchburi provinces. We do not conduct a formal analysis of these qualitative data in this paper but rather employ the data to supplement our survey data with illustrative quotations. For more details on these qualitative interviews, see Knodel and Saengtienchai (2001).

RESULTS

Table 2 illustrates the wide variety of caregiving tasks in which AIDS parents typically engage. Among the specific tasks we asked about, over half of the AIDS parents in our sample provided care at least sometimes in the following areas: preparing food, bathing, cleaning, dressing, feeding, watching over, lifting and moving, help with the toilet, preparing and giving medicines, shopping, transport, and consulting with health care providers. Several of the more physical or time consuming tasks were reported by significantly more parents who coresided with the PHA than by those who did not: bathing, lifting and moving, preparing and giving medications, cleaning wounds, transportation, consultation with health providers, and applying for benefits. When asked about the most difficult aspect of caregiving for their deceased adult child PHA, 30% of those who did not coreside with the PHA responded that it was not problematic, but this was the case for only 21% of the parents who did coreside. Among those parents who coresided, 43% of those responded that it was the caregiving tasks themselves that were the most problematic aspect of caring for their PHA child. Only 13% cited emotional strain, and less than 1% cited negative community reaction as the most difficult aspect.

Among the AIDS parents households, it was unusual for neither parent to have provided any care; only 7% of these households reported this (Table 3a). However, this figure likely overstates the extent of parental involvement in care-giving to adult children infected with HIV, since parents who refused to participate could come disproportionately from households in which the parents did not provide care, perhaps because of estrangement from the ill child or for other reasons that will have a bearing on care-giving. Also, it appears that parents who had children die of AIDS away from their home communities (and for whom giving care would thus be very difficult if not impossible) are underrepresented in this sample of AIDS affected parents.³

In over half of the households in the AIDS parents survey reported here, both the mother and the father participated in caregiving. Parents were not, however, left completely on their own. In none of the AIDS households did either parent (or the pair of them) report that they alone gave care to their ill child (results not shown).

When he was really sick, our children came back to be with us because we were becoming very exhausted. They had to help out because we needed to get some sleep. It was about ten days that we needed our children to help us out because our son was big and we couldn't life him alone. [70 year old mother and 80 year old father, Rayong province]

But even if all of the parents report at least some help with these tasks, it was the parents themselves who were the primary caregivers for both personal and instrumental care. This distribution and burden of caregiving differed for mothers and fathers (Table 3b). Majorities of both mothers and fathers were involved in personal caregiving, but mothers were more likely to be reported as a personal caregiver and as a primary personal caregiver than fathers, at a statistically significant level for both comparisons ($p \leq 0.001$). Substantial proportions of mothers and fathers were reported to be involved in instrumental care, but again mothers were more likely to be reported as an instrumental caregiver and as a primary instrumental caregiver than fathers ($p \leq 0.01$ for both comparisons). In situations where both parents reported providing care, slightly more than half of the cases, mothers were more likely to be reported as providing more personal care than fathers ($p \leq 0.001$). It is clear that fathers as well as mothers are key providers of instrumental care for their ill adult children.

Duration of caregiving, amount of time spent on caregiving, and perceived difficulty of caregiving are reported by the AIDS parents in Table 4. Periods of caregiving were generally quite short, with a median duration of 1 month among households with parents who gave any care and 2 months for households where one parent was a principal caregiver. The intensive of caregiving during these periods, however, was almost overwhelming for some.

At the beginning, he still could walk. Later, when he was almost dead, he could no longer walk...I needed to support him to get up and eat...It's like he did things a lot slower...That's why I had to spoon feed him and shower him. I did everything for him...

³ Another survey of AIDS affected families that we conducted that was based upon the reports of key informants (local health officials) rather than parents has of course no refusals and includes a higher proportion of cases who were living away from their home communities at the time of death. This survey likely results in a more accurate estimate of the proportion of parents who provide care to their children who died of AIDS. Among those young adults who died of AIDS with a parent alive at the time of illness, 77% received some care from a parent and for 59% a parent was a main caregiver (Knodel et al. 2001).

I helped support him to the bathroom...I didn't go anywhere that was far from him [61 year old mother, Phetchaburi province].

Think about it. He couldn't urinate or defecate. He had to sleep on a rubber sheet just like in the hospital. When we took care of him, we had to wear gloves and tried not to touch his blood or anything. When he excreted, there's almost nothing. He was very skinny. We had to be careful when taking care of him. [60 year old father, Bangkok].

Among the couples where one parent was the principal caregiver, over half said that the caregiving took "a great deal of time;" almost two thirds of the mothers reported this level of time commitment. Only a fifth of parents where one was the principal caregiver reported that caregiving took only a little or no time, and this proportion falls to only 13% when only mothers are considered. The distributions of the amount of time devoted to caregiving differs significantly for fathers and mothers ($p = 0.01$), both for parents where at least one gave some care and for parents where one was the principal caregiver; mothers report higher time commitments than fathers.

As the next panel in Table 4 shows, only a quarter of the AIDS parents where one parent gave at least some care reported that caregiving was "not difficult." Among those households in which at least one parent was a principal personal caregiver, mothers are more likely than fathers to report that the caregiving was "extremely difficult," 43% versus 31%, respectively. The distributions of level of difficulty for caregiving for this latter group differs significantly for fathers and mothers ($p = 0.01$).

Table 5 reports current level of happiness and overall health, and changes in these general measures of well being over the past three years for the parental respondents in the AIDS households versus the parental respondents in the control households. AIDS parents are also compared by the degree of involvement they had with caregiving (principal caregiver versus some caregiving versus no caregiving). At the extreme categories of reported level of current happiness, parental respondents for the AIDS households differ from parental respondents for the control households. For example, while 9% of control household mothers report themselves as being very happy, only 3% of AIDS households do so. At the other end of the extreme, 7% of mothers from AIDS households report themselves to be "not at all happy," only 1% of the mothers from the control households report this most extremely negative assessment of their level of happiness. Differences in these distributions of reported happiness for mothers in the case households versus mothers from the control households are significant at the $p = 0.000$ level. The differences between the fathers in the case households and fathers in the control households are not as extreme as they are for them mothers but follow the same pattern; these differences between case and control fathers do not quite reach statistical significance.

Among the parents in the case households, the relationship between level of reported happiness and the intensity of care taking is ambiguous. Mothers who report no care are twice as likely to report being very happy compared to mothers who were a primary caregiver (6% versus 3%), but at the same time are about 3 times as likely to report being not at all happy (17% versus 6%). Fathers follow a similar (but dampened) pattern.

We ask next about the parents' degree of happiness 3 years ago compared to today, since the deaths of their children occurred within the past 3 years. Results are similar for mothers and fathers; both were happier then than now, especially with respect to the control parents. Mothers in AIDS households are more likely than mothers in control households to report that they are

were much happier then than now, and less likely to report that they are more happy now than then ($p = 0.04$). Fathers in AIDS households are more likely than fathers in control households to report that they were either somewhat happier then or much happier then ($p = 0.004$). Comparing parents across caregiving categories, it is the mothers and fathers who gave no care who appear to be the least happy, but these differences do not even approach statistical significance for either mothers or fathers.

Among parents in the case households reporting that they are less happy now than 3 years ago, 42% of mothers and 30% of fathers cite the death of their child as a reason for their diminished happiness. This sex difference is nearly eliminated for mothers and fathers who were primary caregivers, but is greatest for those parents who did not give care.

Interviewer: How are you and your husband doing since the death of your son? Mother: We are not very happy. We miss our son. [60 year old mother, Chiang Mai province]

Father: I miss him. I only have one son. However, I also get over it. He will not come to life no matter what. [65 year old father, Bangkok]

The distributions of health status for mothers in AIDS households versus control households are statistically distinct ($p=0.004$) but it is difficult to conclude which distribution is better. Among mothers in the AIDS households, those who gave no care appear to have the worst health distribution, but this difference is not significant. Regarding parents' perceptions of how their health compared to their same age peers, neither mothers nor fathers from the case households were more likely to rate their health as poorer than their peers than were their control household counterparts. Mothers who did not give care appear more likely to report worse health than peers compared to mothers who did give care, but these differences are not statistically significant.

These consistent, if statistically insignificant, findings that suggest that AIDS parents who do not give care may be worse off than the AIDS parents who do give care are intriguing. If one is willing to entertain the notion that the consistency of these findings suggest an underlying difference that might become clear through the over sampling of AIDS parents who do not give care (only a small fraction of AIDS parents fall into this category), we speculate that poor health may be a reason for some parents to forego caregiving rather than a consequence of caregiving. An alternative suggestion is that as grim as this caregiving experience is for many parents, it offers them an opportunity to fulfill their perceived duty as parents before their child dies, an opportunity denied to the AIDS parents who did not provide such care. This second interpretation is quite consistent with several of our qualitative interviews with older caregivers (Saengtienchai and Knodel 2002), although we do not have a companion set of interviews from non-caregivers to compare.

Well, it's my son. I had to look after him. I didn't think about the troubles. I am his father. I would do anything for my son. [65-year-old father, Bangkok]

As a mother, I wanted my son to be cured... I didn't mind how much I had to pay... My son would never be a burden to me. He's my son... It's his life. I've raised him until then. [51-year-old mother, Phetchaburi]

Table 6 displays our more specific health outcomes by the degree of involvement with caregiving among parents in our AIDS affected households. More than half of all AIDS households fathers and mothers had experienced anxiety and insomnia during the time that they gave care to their child ill with AIDS; this proportion rises to above 70% for mothers and fathers who were primary caregivers.

My son didn't sleep much because he was worried (about his condition). When he didn't sleep, I stayed up, too, because I had to look after him. [61 year old mother, Phetchaburi]

I was exhausted and in pretty bad shape. I didn't get enough sleep, either. I was worried about my son and my granddaughter [60 year old mother, Rayong]

AIDS mothers were more likely to experience these negative outcomes than AIDS fathers for all outcomes (all significant at the 0.05 level or better, except for headaches or stomachaches), except for AIDS fathers who were primary caregivers being slightly more likely to report fatigue than AIDS mothers who were primary caregivers (this difference is not statistically significant). These negative health consequences were experienced frequently by many parents who cared for their children. At least 60% of mothers who were the principal personal caregiver experienced anxiety and sleeplessness often; this was true also for 44% of the fathers who were principal personal caregivers. The general pattern is for more parents who were principal personal caregivers to report experiencing these negative health impacts and experiencing them often compared to parents who had a less prominent role. This is particularly true for men, for whom statistically significant differences are found by level of care for ever experiencing all symptoms; and for frequent experience of fatigue and head/stomach aches ($p \leq 0.05$). Conditioning on level of care leads to statistically significant differences in the proportions of women ever experiencing anxiety and fatigue, and for frequent experience of anxiety – more intense care is associated with a higher proportion reporting the symptom. However, substantial proportions of parents who gave any care also experienced these symptoms and experienced them often.

DISCUSSION AND CONCLUSIONS

Older persons are at much less risk of contracting HIV than are young adults, but this does not mean that they are immune from suffering from this disease. Unlike the situation in developed societies, older parents in the developing countries in which the vast majority of AIDS cases occur provide the bulk of caregiving for infected and ill young adults. More specifically, we find in this analysis that large proportions of older persons with PHA children provide a variety of time consuming and strenuous caregiving services to them, ranging from food preparation to transportation to lifting and moving their children. Such tasks are what parents find most difficult about caring for their child, rather than the financial, emotional, or social strains, and are most common among parents who live with their infected children, which most do.

As anticipated by our conceptual framework depicted in the figure, specific features of the social and cultural context of the Thai HIV/AIDS epidemic predispose significant proportions of mothers and fathers to provide extensive caregiving to their ill children. Our

finding that mothers shoulder the majority of this burden is consistent with Thai conceptions of gender and the strong symbolism surrounding the mother-child bond. While substantial proportions of mothers and fathers provide both personal and instrumental care, mothers are more likely than fathers to provide either type of care and to be a main provider of either type of care. Given the infrequent use of anti retrovirals in Thailand, once serious symptoms appear the health of many PHAs will deteriorate rapidly, thus our finding that periods of caregiving are short but demanding is also as expected.

As predicted by our model, this caregiving is not without consequence for the providers. We find that mothers who have had a child die from AIDS reported lower levels of overall happiness than parents who did not. Mothers and fathers of PHAs who died report lower levels of overall happiness now compared to 3 years ago (before the time of the death of their child) with respect to parents from households that did not experience an adult child death. Among parents reporting that they are less happy now than 3 years ago, 42% of mothers and 30% of fathers cite the death of their child as a reason for their diminished happiness. This sex difference is nearly eliminated for mothers and fathers who were primary caregivers.

Clear differences in self-reported general health status between AIDS parents and control parents are not apparent, a finding that was unexpected. But our more specific measures of ill health show clearly the frequency with which parents who give care to their dying PHA children experience adverse health impacts. Many AIDS parents experience anxiety, insomnia, fatigue, muscle strain, and head and stomach aches during the time they care for their ill children, and many experience these problems often. While mothers were more likely to experience these negative health impacts as a result of caregiving, it was the fathers who expressed the strongest link between level of care and negative health consequences: fathers who were primary caregivers were significantly more likely to experience many of these symptoms and to experience them often than were fathers who gave any care. Thus, per our hypothesis, parents who are more closely involved with caregiving appear to experience more negative impacts on their health, especially among fathers. Other findings regarding the relations between level of care and health impact are intriguing. While it seems clear that principal caregivers suffer more adverse specific health symptoms than non-principal caregivers, other (statistically insignificant) findings suggest that AIDS parents who gave no care may fare worse than AIDS parents who did. This is an area that warrants further research, with a special emphasis on the small minority of parents who do not provide care to their ill adult children suffering from AIDS. Finally, parents report that it is the heavy burden of caregiving that they find most difficult, rather than other features of this very difficult experience, providing further evidence that our hypothesis connecting caregiving with negative health outcomes appears sound.

From a policy perspective, we do not of course advocate advising older parents of PHAs to protect their health by forgoing or even limiting caregiving to their ill children. In Thailand and other countries with medium to high HIV prevalence levels, the suffering of PHAs would be much worse than it is without these massive inputs of time, energy, and money by older parents towards the care of their ill children. But there are many ways in which their efforts could be made easier and more effective by government agencies and private organizations that seek to assist PHAs and their families. New initiatives that encourage parental caregivers to seek support from their social networks and from health personnel, and to take adequate care of their own health should be implemented. Greater access to pain killers, sedatives, and other forms of palliative care, for both the PHAs and their caregivers, would alleviate much suffering and reduce feelings of helplessness. Training workshops for older persons focusing on how to clean

wounds and administer medications properly would benefit both PHAs and their parental caregivers. Financial assistance to help defray the costs of caregiving for parents struggling to pay their bills would reduce the number of older caregivers who do not recover from these financial blows. And advising local health personnel how to identify and treat older persons who are suffering from the substantial physical and mental strains that care taking entails would surely benefit members of this older population as they attempt to relieve the suffering of their loved ones during their final weeks of life.

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Figure: Conceptual Framework Linking Parental Health Outcomes with Parental Caregiving to PHAs

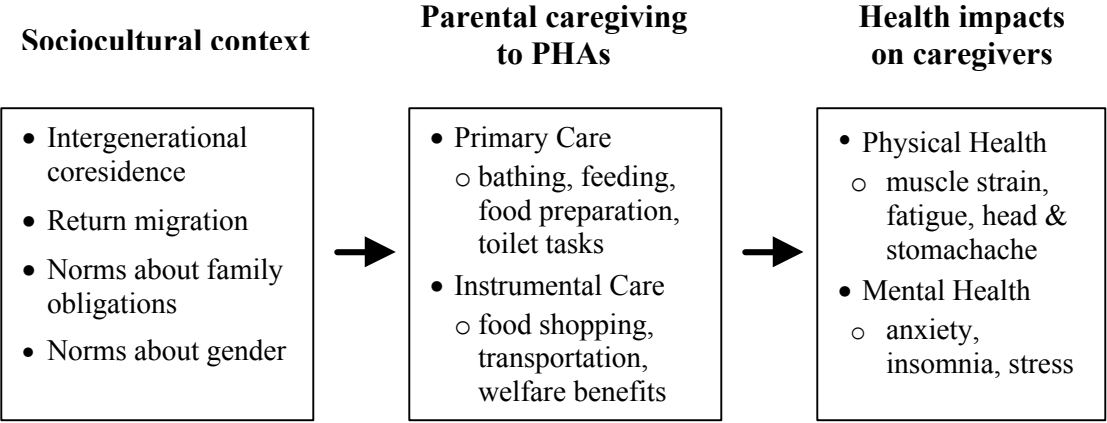


Table 1: AIDS households and control households by basic background and household characteristics

Background Characteristics	AIDS parent households	Control households	All households (total sample)
N of cases	394	376	770
Among married respondents:			
% who were mothers	55	52	53
% with both parents present at interview	37	27	32
Mean age of			
Mothers	60	59	60
Fathers	64	61	62
Educational attainment (% distribution)			
Mother			
less than complete primary	30	28	29
complete primary	69	71	70
more than primary	1	1	1
total	100	100	100
Father			
less than complete primary	20	11	16
complete primary	76	80	78
more than primary	4	9	6
total	100	100	100
Mean number of living children	4	4	4
Mean household size	4	4	4

Notes:

Data are from the household (allparents) file, except for age and education.

Married persons living separately are treated as separated; respondents may be either mother or father.

Table 2: Types of care giving tasks parents perform among those who provided at least some care

Type of task	Proportion of parental households in which a parent performed the task		
	Total	Child lived in same hh as parents	Child lived elsewhere
Preparing food	86	85	86
Bathing	62	64	*51
Cleaning: laundry, dishes	67	69	58
Dressing	61	62	51
Feeding	68	68	67
Watching over	91	92	86
Lifting and moving, e.g., from bed to chair	72	74	*61
Helping with the toilet, changing soiled linens	67	69	56
Preparing and giving medicine (pills or oral fluids)	72	74	*61
Cleaning wounds	17	18	*7
Shopping for food	78	79	74
Transportation, e.g., taking to clinic or hospital	75	77	*63
Consulting with health care providers	65	67	*53
Helping apply for welfare benefits for (name)	23	25	*12
Arranging legal and financial affairs of (name)	17	17	14
Number of households	366	309	57
Most difficult aspect of providing care			
Caregiving tasks	42	43	33
Emotional strain	12	13	9
Financial strain	7	6	9
Negative community reaction	0.3	0.3	0
Not problematic	23	21	30
Other	16	16	19
Total %	100	100	100

Notes:

Data taken from AIDS households file.

Test of differences by location of PHA is by Pearson's chisquare test:

* significant at the 0.05 level

** significant at the 0.01 level

*** significant at the 0.001 level

Table 3a: Proportion of AIDS households in which parents provided care

AIDS households in which:	
-both parents provided care	54
-one parent provided care	39
-neither parent provided care	7
total	100
n	394

Notes: Data are from AIDSparents (household) file.

Table 3b: Proportion of households in which mothers and fathers provided personal and instrumental care

Role in care taking of PHA	Mothers	Fathers	
Was involved in personal care G1a~	***84	56	Both equally or can't say
Was a primary personal care provider G1b~	***60	20	
n	394	394	
Was involved in instrumental care G1c~	**54	43	
Was a primary instrumental care provider G1d~	***36	22	
n	393	393	
If both provided some care,~~ who provided more personal care? G2	***62	19	19
If both provided some care,~~ who provided more instrumental care? G2a	40	42	19
n	207	207	207

Notes:

Data are from AIDSparents (household) file.

~The respondent could list up to 2 primary providers for both personal and instrumental care.

~~Both provided some care in 54% of the cases.

Test of differences by sex of parent is by a paired samples t test.

* significant at the 0.05 level

** significant at the 0.01 level

*** significant at the 0.001 level

Table 4: Care giving duration and burden

Care taking task	Parents of PHAs who gave any care			At least one parent was a principal personal care giver		
	Total	Fathers	Mothers	Total	Fathers	Mothers
Duration of care giving - mean number of months (households)	2.9			3.1		
Duration of care giving - median number of months (households)	1			2		
n	360			276		
How much time devoted to care giving? (individual parents)						
a great deal of time.	44	33	52	52	39	63
some time	25	27	24	27	30	24
only a little time	23	30	17	20	28	13
other	1	3	0	2	4	0
none	7	6	7	0	0	0
Total	100	100	100	100	100	100
n	618	266	352	455	199	256
chisquare significance		0.000			0.000	
Perceived difficulty of care giving (individual parents)						
extremely difficult	32	27	36	38	31	43
somewhat difficult	23	24	22	23	25	22
a little difficult	10	11	9	10	12	9
not difficult	27	29	26	27	29	26
other	1	2	0	1	3	0
none	7	6	7	0	0	0
Total	100	100	100	100	100	100
n	615	264	351	452	197	255
chisquare significance		0.076			0.013	

Notes:

Data are from the household and individual parents files, as specified.

Where mothers and fathers are not reported, “total” refers to the proportion of parental units.

Test of differences by sex of parent is by Pearson's chisquare; exact p values are reported in the table.

Table 5: Distribution of psychological and physical health status by level of involvement in care taking and sex of parent

Features of health status among older persons	AIDS households				Control households	Total
	Respondent was principal personal care giver	Respondent gave some care, but was not principal personal care giver	Respondent gave no care	All AIDS households		
Current level of happiness for R (% distribution) - D1* MOTHERS						
-very happy	3	3	6	3	9	6
-somewhat happy	34	35	39	35	46	40
-neither happy nor sad	37	39	22	36	26	32
-somewhat unhappy	20	15	17	18	18	18
-not at all happy	6	8	17	7	1	4
-total	100	100	100	100	100	100
n	162	66	18	246	226	472
FATHERS						
-very happy	5	4	6	5	9	7
-somewhat happy	27	47	50	40	50	45
-neither happy nor sad	36	31	22	32	29	31
-somewhat unhappy	29	15	17	20	11	15
-not at all happy	2	3	6	3	1	2
-total	100	100	100	100	100	100
n	55	74	18	147	150	297
Total n (mothers and fathers)	217	140	36	393	376	769
Change in happiness over past 3 years for R (% distribution) -D1a* MOTHERS						
-much happier now	2	3	0	2	5	4
-somewhat happier now	18	23	11	19	22	20
-about the same (<i>Skip to D2</i>)	36	29	39	34	39	37
-somewhat happier then	36	38	44	37	29	33
-much happier then	8	8	6	8	4	6
total	100	100	100	100	100	100
n	162	66	18	246	226	472
FATHERS						
-much happier now	5	1	0	3	1	2
-somewhat happier now	11	18	17	15	21	18
-about the same (<i>Skip to D2</i>)	36	34	28	34	48	41
-somewhat happier then	35	43	50	41	28	34
-much happier then	13	4	6	7	2	5
total	100	100	100	100	100	100
n	55	74	18	147	150	297
Total n (mothers and fathers)	217	140	36	393	376	769
Among Rs who are less happy now, *						
-% of mothers who give death of child as a reason	40	47	44	42	0	25
-% of fathers who give death of child as a reason	42	26	10	30	0	18
Total n (mothers and fathers)	98	65	19	182	120	302

Table 5 (continued)

Features of health status among older persons	AIDS households				Control households	Total
	Respondent was principal personal care giver	Respondent gave some care, but was not principal personal caregiver	Respondent gave no care	All AIDS households		
Current reported general health status (% distribution) - D7**						
MOTHERS						
-excellent	9	7	6	8	7	8
-pretty good	28	33	27	29	24	27
-average	13	17	6	13	25	19
-not so good	42	35	39	40	38	39
-poor	8	7	21	9	6	8
-total	100	100	100	100	100	100
n	235	94	33	362	345	707
FATHERS						
-excellent	8	9	12	10	12	11
-pretty good	37	36	31	36	35	35
-average	19	21	14	19	21	20
-not so good	29	28	35	29	25	27
-poor	7	5	8	6	7	7
-total	100	100	100	100	100	100
n	75	159	49	283	276	559
Total n (mothers and fathers)	310	253	82	645	621	1266
Current reported health status relative to others of same age (% distribution) - D7a**						
MOTHERS						
-better	38	37	33	38	28	33
-same	33	35	24	33	43	37
-worse	29	28	42	30	30	30
-total	100	100	100	100	100	100
n	235	94	33	363	345	707
FATHERS						
-better	49	43	47	45	37	41
-same	31	33	27	31	41	36
-worse	20	24	27	24	22	23
-total	100	100	100	100	100	100
n	75	160	49	285	275	559
Total n (mothers and fathers)	310	254	82	648	620	1266
Reported change in health over past 3 years (% distribution)**						
MOTHERS						
-much better	2	3	3	2	3	3
-somewhat better	9	11	6	9	12	11
-same	26	24	30	26	30	28
-somewhat worse	57	52	36	53	48	51
-much worse	7	10	24	9	6	8
-total	100	100	100	100	100	100
n	235	94	33	363	345	707
FATHERS						
-much better	3	2	0	2	4	3
-somewhat better	8	8	2	7	7	7
-same	33	40	37	38	39	38
-somewhat worse	48	44	49	46	44	45
-much worse	8	6	12	8	6	7
-total	100	100	100	100	100	100
n	75	160	49	285	275	559
Total n (mothers and fathers)	310	254	82	648	620	1266

Notes:

Data are from the individual parents file.

*As reported by respondent for self.

** As reported by respondent for self and spouse.

Statistical significance levels are reported in the text for comparisons of interest.

Table 6: Specific psychological and physical health symptoms by level of involvement in care taking and sex of parent

Features of health status among older persons	AIDS households		
	Parent was principal personal care giver	Parent gave some care, but was not principal personal	All AIDS households in which parents gave some care
Specific symptoms of ill health - ever experience**			
MOTHERS			
Anxiety	80	71	78
Insomnia	75	67	73
Fatigue	63	48	59
Strained muscles	49	44	48
Head/stomach ache	36	28	33
n	235	94	329
FATHERS			
Anxiety	71	57	61
Insomnia	73	50	58
Fatigue	67	37	47
Strained muscles	41	24	30
Head/stomach ache	36	20	25
n	75	161	236
Total n (mothers and fathers)	310	255	565
Specific symptoms of ill health - often experience**			
MOTHERS			
Anxiety	68	53	64
Insomnia	60	52	58
Fatigue	43	33	40
Strained muscles	29	29	29
Head/stomach ache	17	18	18
n	235	94	329
FATHERS			
Anxiety	44	45	44
Insomnia	44	35	38
Fatigue	39	22	28
Strained muscles	17	13	14
Head/stomach ache	19	8	11
n	75	161	236
Total n (mothers and fathers)	310	255	565

Notes:

Data are from the individual parents (mom&dadhi) file.

** As reported by respondent for self and spouse.

Parents who did not give care skipped this question.

Statistical significance levels are reported in the text for comparisons of interest.