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Older people and AIDS: quantitative evidence of the impact in Thailand

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Abstract

Discussions of the AIDS epidemic rarely consider the impact on older people except as infected persons. Virtually no systematic quantitative assessments exist of the involvement of parents or other older generation relatives in the living and caretaking arrangements of persons with AIDS in either the West or the developing world. We assess the extent of such types of involvement in Thailand, a country where substantial proportions of elderly parents depend on adult children for support and where co-residence with an adult child is common. Interviews with local key informants in the public health system in rural and urban communities provided quantitative information on a total of 963 adult cases who either had died of AIDS or were currently symptomatic. The results indicate that a substantial proportion of persons with AIDS move back to their communities of origin at some stage of the illness. Two-thirds of the adults who died of an AIDS-related disease either lived with or adjacent to a parent by the terminal stage of illness and a parent, usually the mother, acted as a main caregiver for about half. For 70%, either a parent or other older generation relative provided at least some care. The vast majority of the parents were aged 50 or more and many were aged 60 or older. This extent of older generation involvement appears to be far greater than in Western countries such as the US. We interpret the difference as reflecting the contrasting epidemiological and socio-cultural situations in Thailand and the West. The fact that older people in Thailand, and probably many other developing countries, are extensively impacted by the AIDS epidemic through their involvement with their infected adult children has important implications for public health programs that address caretaker education and social and economic support. © 2001 Elsevier Science Ltd. All rights reserved.

Keywords: AIDS; Older persons; Thailand; Caregiving; Living arrangements

Introduction

HIV/AIDS is usually viewed as a disease affecting reproductive age adults and their infant children.

Discussions rarely consider the impact on older persons and when they do, they typically focus on those who are infected themselves (e.g. Nokes, 1996; Riley, Ory & Zablotsky, 1989; Ory, Zablotsky & Crystal, 1998a). A far greater number of older persons, however, are affected through the infection of their adult children or other younger relatives (Allers, 1990; Brabant, 1994; Levine-Perkell, 1996; Ory & Mack, 1998). Impacts of AIDS on parents can occur through numerous routes

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including: (1) strains of caregiving and associated opportunity costs; (2) providing financial and material support; (3) raising surviving grandchildren; (4) suffering emotional stress; and (5) losing old-age support that the child would have provided (VanLandingham, Knodel, Im-em & Saengtienchai, 2000). The impact of AIDS compared to other diseases can be particularly severe given the lengthy periods of illness and disability, the untimely nature of the death, and possible negative community reactions to persons with AIDS and their families (Mullan, 1998; Brown & Sankar, 1998; Ellis & Muschkin, 1996). Yet few studies focus on older people as parents of persons with AIDS (see, however, Brabant, 1994; Ellis & Muschkin, 1996; Levine-Perkell, 1996; Mullan, 1998; Nazon & Levine-Perkell, 1996; Sankar, Luborsky, Rwabuhemba & Songwathana, 1998). Even rarer are quantitative assessments of how frequently this dimension of the epidemic impacts the older population.

The limited literature on AIDS and older persons relates mainly to the United States or other developed countries. The applicability of this literature based on the US to other settings is constrained by the fact that these studies frequently focus on the special problems and circumstances of AIDS caregiving within the gay community. Moreover, those existing studies rarely provide quantitative assessments (see, however, Crystal & Schiller, 1993; LeBlanc London & Aneshensel, 1997; Mullan, 1998; Turner & Catania, 1997; Turner Catania & Gagnon, 1994; Turner, Pearlin & Mullan, 1998). Perspectives from other settings are necessary to understand the fuller range of societal responses to the epidemic and how they are conditioned by the combination of culture, political system, and levels of social and economic development (Ory, Zablotsky & Crystal, 1998b; Sankar et al., 1998; Spira, Giami & Micheals, 1998). Some consequences for the older generation are likely to be even more pronounced in developing countries where HIV prevalence is often much higher than in the US and where dependence on intergenerational arrangements for caregiving and support is more pervasive.

The present study assesses the extent of the impact of the AIDS epidemic on older persons in Thailand through the illness and death of their adult children or relatives. Thailand is particularly well suited for such a study in a developing country context. The Thai AIDS epidemic is the most advanced in Asia (UNAIDS/WHO, 1998; MAP, 1998) and sufficiently far along for repercussions to be manifest and thus suitable for systematic investigation. Moreover, good quality epidemiological data on AIDS and extensive research into the general situation of the older population are available to provide important background information (e.g. Brown, Sittitrai & Thisyakorn, 1994; Knodel, Chayovan, Graiurapong & Suraratdecha, 2000; UNAIDS, 1998a,b).

The Thai setting

Recent estimates indicate that almost 800,000 Thais had been infected by HIV by the end of 1997 and 260,000 had already died of AIDS, with 60,000 dying in 1997 alone (UNAIDS, 1998a). Although incidence has fallen in response to aggressive organized efforts to combat the epidemic (Phoolcharoen, Ungchusak, Sittitrai & Brown, 1998; UNAIDS, 1998b), UN and Thai government projections both indicate that deaths will increase for some years to come (NESDB, 1994; UN, 1999). In several upper northern provinces where the epidemic has been the worst, the increase in the overall death rate which more than doubled between 1990 and 1996 is believed to be due to tens of thousands of deaths thought to be caused by AIDS (van Griensven, Surasiengsunk & Panza, 1998).

In common with most developing countries, heterosexual intercourse is the overwhelming route of HIV transmission in Thailand (well over 80% of cases reported through 1999). Intravenous drug use accounts for 5% and homosexual/bisexual relations for only 1%. Much of the epidemic has been driven by commercial sex patronage although infected men are increasingly spreading the virus to their wives and non-commercial partners (Brown & Sittitrai, 1995; Brown & Xenos, 1994; Ford & Koetsawang, 1991).

As in much of the developing world, a familial system of intergenerational exchanges of services and material support remains pervasive in Thailand (World Bank, 1994). Widespread norms support filial obligations to parents, including expectations of old-age support in the form of remittances, co-residence and visits (Knodel, Saengtienchai & Sittitrai, 1995). As recently as 1995, nearly three-quarters of parents aged 60 or above coresided with an adult child and 90% either lived with or had daily contact with one. Among persons aged 60 or over with children living outside the household, 89% received food or clothes from them during the prior year, 88% received money, and 69% received significant amounts (defined as US\$30 or more). Almost half (49%) reported their children as their main source of support (Knodel et al., 2000).

One result of this familial system of intergenerational support exchanges is that substantial proportions of adult children live with or near to parents. If a coresident child marries and moves out of the parental household it is often to a dwelling in the same compound or community. According to the nationally representative 1995 Survey of Welfare of Elderly in Thailand (SWET), one-fourth of children aged 15 and over of parents aged 50 and over co-resided with their parents and another fourth lived either adjacent to parents or in the same local community (original tabulations). Moreover, rural Thais tend to maintain strong attachments to their community of origin,

especially when their parents remain there. This is evident from the data collected in the 1995 SWET which indicates that almost 90% of adult children who lived outside the local community of their parents returned to visit their parents during the prior year and two-thirds of those, returned had visited at least several times.

In brief, in comparison with more affluent countries, Thailand shares important characteristics with other developing country settings that are likely to be critical for understanding the implications of the AIDS epidemic for older persons. Thus the findings of the present study have considerable relevance for other developing countries that are also experiencing an increasing burden of AIDS including many where levels are much higher.

Data and methods

Key informant approach

Drawing a reasonably unbiased and sufficiently large sample of cases poses formidable challenges for any attempt to quantitatively study the impact of AIDS on parents of infected persons (Mullan, 1998). The difficulties arise both from the need to be able to identify appropriate cases and the sensitive nature of subject matter being investigated. The strategy we employed to minimize these problems was to interview key informants in the public health system to provide individual case information. We selected informants who were likely to know who in their local area was ill with or died of AIDS along with basic information about them: age, sex, marital status, existence of dependent children, living status of parents at time of illness, if and how long the person lived with a parent, change of residence during illness, and who provided care. For a subset of these cases whom the key informant knew best, we asked supplemental questions about community reaction, economic status, financial arrangements, economic impact on the family, and ages, health and location of parents. All interviews were conducted by the principal investigators (the current authors) and occurred primarily during the first half of 1999.1 To protect confidentiality, names of individual cases were not recorded.

We conducted the study in 85 sites in eight provinces and Bangkok. The provincial samples were drawn from all major regions of Thailand and included both rural and urban sites in each province.² To maximize the

number of cases for which we could obtain information, we chose provinces with relatively high AIDS levels for the region based on HIV infection levels among military recruits during 1991–1998. Nevertheless, because there is sharp regional variation in the level of the epidemic, the selected provinces differ considerably in the levels of HIV among recruits, ranging from 8–9% in the two upper northern provinces to under 2% in the two northeastern ones.

For most rural sites, informants were staff of community (Tambol) health stations, the lowest level facility in the Thai Public Health system. We chose sites where a staff member was either a local person or lived in that place long enough to know the community well. The selected stations were responsible for a median of 1100 households. Most informants appeared confident in their ability to identify AIDS-related deaths within their local area of responsibility. Identification of currently symptomatic cases was probably less complete since the onset of illness is less likely than a death to become widely known. The key informants' information came from many sources including notification from higher level facilities, visits to the health station by the person with AIDS or their relatives, home visits, the extensive network of village health volunteers, and funerals. Given differences in the public health system in urban areas (e.g. community health stations generally do not exist) and the greater anonymity of urban settings, we drew urban informants from varied sources, the most important of which was the corps of urban neighborhood health volunteers but that also included community leaders, welfare workers, home-visiting nurses, and other health personnel.

A key informant approach carries potential risks. Informants might be selective in their familiarity with cases in ways that could bias results. For example, the key informants might be more familiar with cases who had lingering illness and higher care needs or who were cared for by an extended family compared to those who died after an acute first episode or were cared for more privately (e.g. by only a spouse). Likewise they might be more familiar with cases of longer established members of the community or with cases with more social or medical needs. Such biases are probably more likely to affect reporting of cases who are currently ill than cases who already had died since a death becomes quickly and widely known and funerals are quite public affairs in Thailand. Additional biases could arise from presumptions made by the key informant rather than actual observations about the cases. When studying a stigmatized disease such as AIDS, however, these risks need to be weighed against the potentially more serious biases that characterize common alternative approaches such as those based on volunteers, self-identified cases, or attempted random samples that suffer from extremely

¹The two Thai authors were the main interviewers. The two US authors both speak Thai and when present contributed occasionally to the interview.

²The specific provinces were Rayong and Petchaburi in the central region, Khon Kaen and Ubon in the northeast, Chiang Mai and Chiang Rai in the upper north, Phichit in the lower north, and Phuket in the south.

low-response rates (Levy & Albrecht, 1989). Moreover, as shown below, the sample we obtained is quite similar to AIDS cases in general on numerous important dimensions relevant for our analysis.

keep interview length manageable, usually limited the number of cases for which basic information was requested to a maximum of 20 per site who had died locally of AIDS and five who were currently symptomatic and living in the community. We asked the supplemental questions described above for a maximum of six adult cases, giving priority to those who had already died. When the potential cases exceeded our limit, we gave precedence to those who were adults (age 15 +), who had died more recently, and for whom the informant felt more confident about the information being requested. We also asked limited information about cases who had presented symptoms while in the community but left before dying and cases whose parents lived in the community but who died elsewhere. In total, we obtained basic information on living arrangements and caretaking for 1032 adult cases (defined as age 15 or over) who were currently ill with or had died of AIDS.3 Our quantitative analysis, however, is restricted to the 963 adult cases (including 285 for which supplemental information was collected as described above) who either were still present with symptoms (195 cases) or died locally (768 cases). The restriction to these cases was made for two reasons. Most importantly, persons with AIDS who left the locale or who were elsewhere during their entire illness would theoretically have twice the chance of being included in our sample, once at their place of origin and once at their place of destination, than persons who were present or died in the locale. Secondly, less information was asked about the excluded cases because informants generally did not know many details about them for the period they were not in the community.

Depending on the particular results presented in the following tables, the unit of analysis can either be the AIDS case (Tables 1–3) or the parent of the AIDS case (Tables 4 and 5). The labeling of each table makes clear which unit of analysis is being used. Where the unit of analysis is the AIDS case and the focus is specifically on the involvement of parents (Tables 1 and 2), results are presented both for all cases and for cases who have a living parent. In the latter situation (i.e. for results based on AIDS cases who had a living parent), we adjust the results to allow for the 8% of cases for whom the informant was uncertain if a parent was alive (typically

involving cases who were non-local spouses of local persons).⁴ When the unit of analysis is the parent, we draw the data from the subset of AIDS cases for which supplemental information was collected about the parents. The total number of parents for whom such information is available is 393, however the analyses presented here are limited to the 360 parents of cases who had already died of AIDS.⁵

Sample comparability

Our sample based on key informant information is clearly not designed to be nationally representative in any statistical sense. Nevertheless, it is instructive to compare it in terms of important characteristics that are likely to bear on our results with what would be expected from a truly representative sample. To do this we draw on independent external sources of information that are intended to be nationally representative, primarily the national registry of AIDS cases maintained by the Ministry of Public Health and the 1994 National Survey of the Elderly conducted by the National Statistical Office (no date).

Two-thirds of the adult cases are drawn from rural settings, with the remainder divided almost equally between officially designated municipal areas and periurban areas (either on the fringes of municipal areas or urbanized in appearance). Although information on the rural–urban distribution of registered AIDS cases is not available, we note that the distribution of our sample closely resembles that of the national population in general.⁶

³We also received information on 37 cases of children under age 15 who died. However, given our interest on the impact on older persons we limit our consideration to adult cases given that the parents of younger children tend to be relatively young themselves.

⁴In many of these cases the parents are likely to be alive. However, since informants are probably more likely to know of living than dead parents (e.g. the parents may have visited the community), these unknown cases are probably skewed towards persons with deceased parents. Thus in the calculations we assume that the proportion with a living parent is two-thirds that of the equivalent 5-year age group based on cases for whom the parents' living status is known. Given the small percentage of cases involved, results are only minimally affected by this assumption.

⁵This is greater than the number of cases for which supplemental information was collected reflecting the fact that some of the cases had two living parents (at the time of illness) and information is available for both parents in these cases.

⁶Exact comparisons with official statistics cannot be made since our classification is based on a combination of official definitions (for municipal areas) and observation (for rural and peri-urban areas). However, a rough idea of the similarity with the national distribution is provided by a comparison with the nationally representative household sample of the 1994 the National Survey of Elderly which indicates 70% of the population was rural and 30% were either in officially designated municipal areas or sanitary districts (essentially peri-urban areas).

Table 1 Indicators of parents' and older generation persons' role in living arrangements and caregiving for persons aged 15 or older who died of an AIDS-related disease or are living with symptomatic HIV

	Persons who died of an AIDS-related disease		Persons with symptomatic HIV		
	Mean incidence	Standard error	Mean incidence	Standard error	
All cases					
% co-reside with parent when ill	58.8	1.8	49.0	3.6	
% co-reside with or live next to					
parent when ill	66.5	1.7	56.7	3.6	
% for whom parent provided care	64.5	1.8	34.8	3.5	
% for whom parent was a main caregiver	49.7	1.8	26.7	3.2	
% for whom any older generation person					
provided care	70.2	1.7	38.5	3.6	
% for whom any older generation person					
was a main caregiver	53.8	1.8	28.9	3.3	
Number of cases ^a	754/738		194/187		
Cases with at least one living parent —adjusted estimates ^b					
% co-reside with parent when ill	69.7	1.8	60.6	3.8	
% co-reside with or live next to	70.0	1.6	70.1	2.6	
parent when ill	78.8	1.6	70.1	3.6	
% for whom parent provided care	76.9	1.7	42.1	3.9	
% for whom parent was a main caregiver	59.3	1.9	32.4	3.7	
No. of cases ^a	659/645		164/162		

^aThe first number refers to the number of cases with non-missing values for the two living arrangement measures and the second number refers to the number of cases with non-missing values for the two caregiving measures.

With regards to sex distribution, 26% of our adult sample are women compared to 23% among nationally registered AIDS cases reported for 1997–1998. Thus overall our sample is only modestly more weighted towards women compared to all reported cases. Fig. 1 presents additional comparisons. Panel A shows that the age distribution of persons living with or who died of an

AIDS-related disease in our sample is almost identical to that of nationally reported AIDS cases. Panel B indicates that the marital status distribution of the sample is reasonably consistent with that of nationally reported AIDS cases. In both, married persons are clearly the most common, followed by single persons. Our sample, however, has a higher proportion of formerly married persons than among nationally reported AIDS cases. This reflects in part the modestly higher proportion of women in our sample, among whom a much higher proportion are widowed, separated or divorced than among the male AIDS cases. In our sample, 42% of women living with or who died of an AIDS-related disease were formerly married compared to 14% of men (not shown). The main reason for the gender difference in marital statuses lies in the dynamics of the Thai epidemic where men have usually been infected first, typically through commercial sex contact and then later transmitted HIV to their wives. Thus, infected women usually had an infected husband many of whom had died

Panel C shows that the proportions of our sample of AIDS cases with a surviving parent are similar to the proportions in the equivalent age group with a living

^b Estimates are adjusted for cases for which the key informant did not know the living status of the parents. See text.

⁷This and the following comparisons focus on reported cases for 1997–1998 since our sample is skewed towards recent cases reflecting the selection process and the timing of fieldwork.

⁸The proportion of our sample that consists of currently symptomatic cases, however, is particularly high in its representation of women (43%) and accounts for the higher overall percentage of women. This may reflect a greater ease for local health personnel in identifying symptomatic women than men. In many cases, the women contracted HIV from their husbands whose earlier death alerts the informant of the possibility the wife may be infected and to be on the lookout for symptoms. Also pregnant women are routinely tested as part of antenatal care and local health personnel sometimes learn when a woman tests positive. This overrepresentation of women does not characterize the sample who died of an AIDS-related disease because death, as opposed to onset of symptoms, quickly becomes public knowledge regardless of sex.

Table 2
Indicators of parents' role in living arrangements and caregiving for persons aged 15 or older who died of an AIDS-related disease, by demographic characteristics of the AIDS case, unadjusted and adjusted by logistic regression^a

Demographic No. of cases ^b characteristic of AIDS case		% who lived with a parent when ill				% for whom parent is main caregiver			
of AIDS case		All cases		1+ parent alive ^c		All cases		1+ parent alive ^c	
		Unadjusted	Adjusted	Unadjusted	Adjusted	Unadjusted	Adjusted	Unadjusted	Adjusted
Age			(p = 0.000)		(p = 0.000)		(p = 0.000)		(p = 0.003)
15–29	304-275	71.1	68.8	77.7	75.4	59.7	55.9	65.3	61.2
30-39	321-292	61.1	61.4	67.6	68.2	53.7	54.6	59.6	60.6
40 +	129–78	24.0	27.2	45.7	50.1	17.7	21.2	34.2	40.8
Sex			(p = 0.533)		(p = 0.656)		(p = 0.091)		(p = 0.045)
Male	587-499	59.4	58.9	70.0	69.2	48.6	47.8	57.5	56.4
Female	167–146	56.3	56.4	68.5	67.2	53.6	54.7	65.6	65.0
Marital status			(p = 0.000)		(p = 0.000)		(p = 0.000)		(p = 0.000)
Single	242-213	81.0	60.2	90.5	70.6	76.6	51.5	86.0	60.2
Sep./divorced	64-53	68.8	57.3	82.2	62.7	66.1	48.1	79.6	53.4
Widowed	68-51	48.5	42.7	71.1	50.9	47.1	33.7	70.0	41.9
Married	373–322	44.0	43.9	52.5	52.6	29.3	29.5	35.1	35.3
Residence			(p = 0.000)		(p = 0.002)		(p = 0.001)		(p = 0.008)
Rural	516-446	64.0	62.7	73.4	72.3	54.2	53.2	62.6	61.5
Urban	238-199	47.4	48.6	60.6	60.6	40.4	41.1	51.7	51.5

^aThe figures adjusted by logistic regression represent the mean predicted probabilities taking into account the other demographic characteristics included in the table. All characteristics are treated as categorical variables in the regression. The *p*-values indicate statistical significance of the set of categories based on the Wald statistic.

^bThe range represents the maximum and minimum number of cases on which results in each row are based.

^cEstimates are adjusted for cases for which the key informant did not know the living status of the parents. See text.

Table 3
Mean age at death, percent who had a living parent, percent who lived with a parent, and percent who had caregivers of particular types among adults dying of AIDS, by sex and marital status of person dying of an AIDS-related disease^a

	Total	Sex		Marital status			
		Male	Female	Single	Separated/divorced	Widowed	Currently married
No. of cases ^b	738°	570	168	235	62	70	365
Mean age at death	33.0	33.4	31.6	29.8	34.6	40.0	33.5
% having a living parent ^d	82.3	83.4	78.6	88.3	82.0	65.2	81.3
% for whom main caregiver was:							
Parent	49.7	48.6	53.6	76.6	66.1	47.1	29.3
Other older generation person	4.2	3.9	5.4	5.1	1.6	7.1	3.6
Spouse	31.6	35.3	19.0	_	_	_	63.8
Sibling	10.8	10.9	10.7	15.7	22.6	11.4	5.8
Child/child-in-law	3.8	2.6	7.7	_	3.2	30.0	1.4
Other	3.1	2.8	4.2	5.1	4.8	5.7	1.1
% for whom any caregiver was:							
Parent	64.5	64.9	63.1	80.9	69.4	54.3	54.5
Other older generation person	7.7	6.8	10.7	7.7	3.2	7.1	8.8
Spouse	35.2	38.8	23.2	_	_	_	71.2
Sibling	26.0	26.0	26.2	37.9	45.2	27.1	15.3
Child/child-in-law	7.0	6.0	10.7	_	4.8	32.9	7.1
Other	7.7	6.5	11.9	8.9	12.9	18.6	4.1

^a All results refer to the situation at the terminal stage of illness. The sum of the percents of each type of caregiver exceeds 100 since for some persons dying of AIDS, the key informant reported more than one type of caregiver including 5% of cases for whom more than one type of main caregiver was reported. (—) = not applicable.

parent among the general population as found in the 1994 the National Survey of Elderly. Finally, panel D indicates that the age distribution of the parents of the AIDS cases in our sample as reported by the key informants is very similar to what would be expected based on the age distribution of parents of adults in the general population who are in the same age groups as the adult AIDS cases in our sample. ¹⁰

In brief, these comparisons taken together suggest that cases reported by the key informants resemble remarkably well the national population of recent AIDS cases in Thailand on several important dimensions. Cases reported by our key informants thus should provide a reasonably representative sample for analyses relating Thai AIDS cases and their parents.

Inclusion of return migrants

For persons with AIDS, living and caretaking arrangements often change during the course of the illness. Many are able to care for themselves initially but at later stages require assistance. Thus some who live away from their place of origin at the onset of symptoms return when they can no longer earn a living or need care assistance (Brabant, 1994; Ellis & Muschkin, 1996; Sankar et al., 1998). Among our total adult sample, 37% of those who had died had returned to their place of origin after becoming ill and the large majority (77%) moved in with parents or adjacent to them. 11 Some

^bRefers to the number of cases with caregiving information; mean age at death and the percentage with a living parent is based on a slightly larger number of cases.

^cIncludes 6 cases of unknown marital status.

^d Estimates are adjusted for cases for which the key informant did not know the living status of the parents. See text.

⁹Although, as the title implies, the main purpose of the survey was to collect information on older persons (aged 50+), it also included questions directed to a nationally representative sample of all households regardless of the presence of older household members.

¹⁰The expected age distribution of parents of adults with AIDS in our sample was calculated from a matrix which showed the percentage age distribution of living mothers and living fathers for adults in each age group in the general population (as provided in the 1994 Survey of Elderly in Thailand). By weighting that matrix by the proportionate age distribution of AIDS cases in our sample, we obtain the expected age distributions of living mothers and fathers assuming that the AIDS cases in each age group had living parents of similar ages as the equivalent age groups of adults in the general population. By combining mothers and fathers, we obtain the expected age distribution of parents.

¹¹ A substantial share (at least half) of those who moved back and did not live with or next to parents had no living parent. Some of them may have moved in with older generation relatives but we do not have information on this.

waited until the illness was very advanced. For example, about a third (32%) of those who returned when ill lived no longer than a few months, including some who died after just a few weeks or even a few days following their return. In contrast, rarely were cases reported to have left their place of origin to die elsewhere.

Such a high return rate is quite plausible in the Thai context. Unless migrants are married and their spouse remains with them to provide care and financial support, they often have nowhere else to go. Thai hospitals shy away from long-term care of AIDS cases and hospices have limited capacities. Moreover, there are undoubtedly strong personal emotional advantages of being at home to die. Nevertheless, it is important to consider if our sample design could potentially bias our results in this respect. In Thailand, many young adults migrate from their parental home in the provinces to find work in urban centers, especially Bangkok. Although Bangkok and other urban places are in our sample, the number of cases from these places, the non-random nature of our sampling of sites within urban areas, and/or selective familiarity on the part of key informants with cases involving native persons could potentially skew our results towards cases who return to their place of origin. If adults who migrated to Bangkok (or elsewhere) and died of AIDS without returning to their parental home before death are large in number and substantially underrepresented in our data, this would result in our overestimating the extent of parental involvement with AIDS.

We followed several strategies to assess this problem and they all suggest that the extent of any such bias is likely to be small. First, we interviewed staff of four major organizations who assisted large numbers of persons with AIDS in Bangkok. They consistently reported that despite common initial hesitancy to reveal their situation to their parents, most migrants eventually return home, especially once they became too ill to work. Second, we identified 18 cases in the Bangkok sample sites who were migrants from the provinces. Two-thirds were reported to have returned to their provincial home after becoming ill. Several others left the community to destinations unknown to the informant. Third, when we directly asked provincial key informants about this matter, almost all agreed that the vast majority of AIDS cases would return to be with their parents before dying. Cases of adult children who died away from the parental home were reported in only a fourth of the provincial sites and in about half of these, only one case was known.

The link between migration and stage of illness has implications for estimates of the percentages of parents who co-reside with adult children with AIDS and who contribute to caregiving. Because of return migration during the illness, the extent of parental involvement is

fully evident only for cases who have already died of AIDS. We thus focus much of the analysis on persons who have died of AIDS and include both adult children who were living in the area in which they died when symptoms first appeared and those who returned after the onset of symptoms.

Results

Living and caregiving arrangements

Several basic measures of living and caregiving arrangements of AIDS cases in relation to older generation persons are summarized in Table 1. They refer to the current situation for those still living and to the terminal stage of illness for those who died. For the measures relating to parents, additional results are shown conditioned on the availability of a living parent, adjusted for the small proportion of cases for whom the informant did not know if a parent was alive, as described above. Such an adjustment is necessary since cases for whom the living status of parents is unknown are necessarily selective of those who did not co-reside with parents or receive parental care (if they had, it would be known that a parent was alive). Ignoring these cases would artificially inflate the indicated levels of parental involvement.

As expected from the fact that substantial numbers of persons with AIDS only return home at later stages of illness, the measures consistently show higher percentages of parental and overall older generation involvement for cases who already died of AIDS compared to currently symptomatic cases. An even greater difference is evident between these two groups for the caregiving measures. This likely reflects the increasing need for assistance as the illness progresses. Indeed half of the currently symptomatic cases were still caring for themselves while almost all who died were given care by others (not shown).

Older generation persons in Thailand are commonly involved with the living and caretaking arrangements of persons with AIDS. A majority (59%) of those who died of an AIDS-related disease co-resided with a parent at the terminal stage. Moreover, two-thirds either co-resided or lived next door, reflecting the fact that married children, especially in rural Thailand, often live in the same family compound (Knodel & Saengtienchai, 1999). These percentages are even higher (69 and 79% respectively) when only cases with a living parent are considered.

Caregiving also commonly involves parents. Parents provided care for almost two-thirds of those who died of an AIDS-related disease and were the main caregiver for half. For those with a living parent, more than three-fourths received some care from a parent and for almost 60% of cases a parent was a main caregiver. Even when

a parent was not involved, other older generation relatives sometimes played a caregiving role. Thus 70% of adults with AIDS were cared for by someone of the older generation if both parents and relatives are taken into account.

Characteristics of AIDS cases

Table 2 focuses on how demographic characteristics of adults who died of an AIDS-related disease relate to co-residence with parents and having a parent as a main caretaker (the two more intensive measures of parental involvement). Results are shown both for all adults who died and also for those with a living parent (additionally adjusted to allow for cases where the living status of the parent is unknown). In addition to simple bivariate associations, results are also provided that are statistically adjusted through logistic regression. The adjusted results indicate the association with each characteristic net of the influence of the other characteristics included in the table and are presented as mean predicted probabilities to facilitate interpretation. ¹²

The unadjusted results for all cases as well as cases conditioned on having a living parent show that both co-residence with a parent and having a parent as a main caretaker decrease with age, especially for the oldest. The negative associations with age are somewhat less pronounced when conditioned on having a parent alive but are still quite strong. Statistical adjustment for associations with the other variables only modestly attenuates the negative relation with age. The sex of the person dying with AIDS shows little relationship with co-residence with a parent but women seem modestly more likely to have a parent as a main caretaker than do men. Neither conditioning on having a parent alive nor statistical adjustment for the other variables has much impact on the weak association with sex.

A quite strong relationship exists between parental involvement and the marital status of the person who dies of AIDS. Indeed, a substantial majority of single and separated or divorced adult children who died of an AIDS-related disease lived with a parent at the terminal stage of illness. Likewise parents served as main caregivers for most of these children. Widowed and currently married cases were considerably less likely to live with parents or have a parent as a main caregiver.

This lower level of parental involvement for widowed cases is in large part due to their lower chances of having a living parent (given that they are considerably older than other cases on average — see Table 3). Once results are conditioned on availability of a living parent, the tendency to co-reside with a parent when ill or to have a parent as a main caregiver among widowed is more similar to separated or divorced cases than to married ones. Even for overall cases, however, substantial shares of both widowed and married persons dying of AIDS lived with or were taken care of by a parent in the final period. Given the association between age and marital status, it is not surprising that the extent of marital status differentials is reduced after statistical adjustment. Nevertheless, even the adjusted association remains pronounced.

Finally, living with a parent when ill and having a parent as a main caregiver is more common for rural than urban cases. This remains the case both when conditioned on availability of a living parent and after statistical adjustment for the other variables.

Parental versus other caregivers

Parents of course are not the only persons who provide informal care to adult persons with AIDS (PWAs). Table 3 shows the frequency with which a parent serves as caretaker for adults who died of an AIDS-related disease compared to other persons. Results are shown according to the sex and marital status of persons who died of an AIDS-related disease. To aid in interpretation of the results, the table also shows the mean age of death and the percentage who have a living parent (which are obviously related). In general, men and women who die of AIDS differ only modestly in these respects. However, some substantial differences are evident by marital status in both respects. As noted above, widowed persons dying of AIDS are considerably older than average and single persons are somewhat younger.

Overall, parents are clearly the most common caregivers, well ahead of spouses who take second place (but who are the most common caregiver in cases of married persons with AIDS). The main difference in the configuration of caregivers for men and women with AIDS is with respect to the percent for whom a spouse was a caretaker. Men are much more likely to have been cared for by their wives than the reverse. Given that for both men and women who died, about half were currently married (not shown), the difference reflects the greater tendency for women than men to be caregivers. Also, currently married women PWAs may be more likely than married male PWAs to have a spouse who is already ill, reflecting — as noted above the specific dynamics of the Thai epidemic, in which men typically are infected through commercial sex patronage

¹² To derive adjusted percentages for each particular category of the variables shown, we first calculated a predicted probability for each individual included in the analysis on the basis of the logistic regression coefficients. We assumed that all individuals fall into the particular category under consideration but retain their actual values with respect to all other control variables. Then we calculated the adjusted percentage as the mean of the predicted probabilities for that category for all individuals included in the analysis.

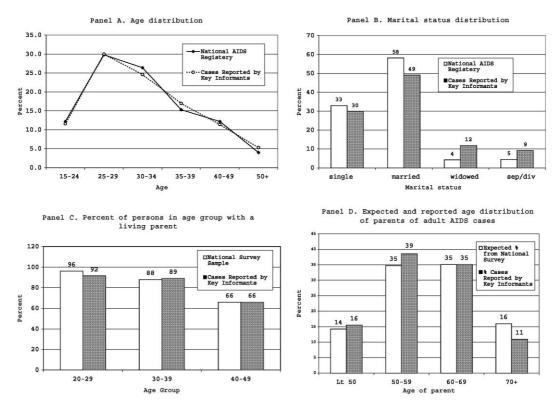


Fig. 1. Comparison of selected characteristics of study sample based on information from key informants with expected characteristics based on independent external sources. Sources of external data: Special tabulations from Thailand, Ministry of Public Health, AIDS Division (Panels A and B); Original tabulations from Thailand, National Statistical Office, 1994 Survey of Elderly in Thailand (Panels C and D). Notes: Estimates in Panel C are adjusted for cases for which the key informant did not know the living status of the parents (see text). Estimates in Panel D compare the age distribution of parents of adults in the general population who are in the same age groups as the adult AIDS cases in our sample.

(often when still single) and only later pass on the virus to their wives.

The configuration of caregivers varies considerably with the marital status of the person who died of an AIDS-related disease. For those who are still single at death, a parent was a main caregiver in over three-fourths of the cases and provided at least some care for over four-fifths. Parents were also the most common caregivers (main or otherwise) for separated and divorced as well as for widowed children. For widowed cases, however, children of the person who died were very common compared to other cases. This is likely related to the older age at death of widowed cases which results in their being more likely to have children old enough to contribute to caregiving but less likely to have a living parent to provide caregiving.

The one group for whom parents were not the predominant caregivers is persons who were currently married when they died of AIDS. Spouses served as a main caregiver for almost two-thirds of these cases and provided at least some care for over 70%. Still, even for

married AIDS cases, parents are frequently involved as a main caretaker and provide at least some care for more than half of these cases. We note that even among married cases, a third had returned from elsewhere since the onset of illness (not shown). A few returned because both spouses were ill. More commonly, however, the return appears prompted by the need for caretak-ing assistance by the spouse who was well. This is suggested by the fact that in over 40% of cases where a married couple returned, a parent acted as a main caregiver and in almost two-thirds assisted in caregiving (not shown).

Caregiver characteristics

Information on the characteristics of the parents of adults who died of an AIDS-related disease and how they relate to involvement with living and caretaking arrangements is available for the subset of cases about which we asked additional questions. Results presented in Tables 4 and 5 refer to parents who were alive at the time of the child's death. Table 4 shows the

Table 4
Percentage distribution of all parents of adult children who died of an AIDS-related disease, of parents who co-resided with the child, of parents who gave any care to the child, and of parents who gave main care to the child, according to selected characteristics of the parent^a

Characteristic of parent	All parents	Co-resident parents	Providing any care	Main care-givers	
Total	100	100	100		
Age					
< 50	14.8	16.5	15.9	17.4	
50—59	37.2	39.3	40.7	43.1	
60—69	37.2	35.7	35.8	33.3	
70+	10.7	8.5	7.5	6.3	
Sex					
Father	41.9	37.7	30.3	15.9	
Mother	58.1	62.3	69.7	84.1	
Health status					
Good	79.4	80.3	80.9	78.5	
Minor problem	9.8	9.0	9.8	11.8	
Poor	10.8	10.8	9.3	9.7	
Economic status					
Good	23.2	22.1	23.4	20.9	
Average	50.2	52.7	51.4	51.8	
Poor	26.2	25.2	25.2	27.3	
No. of cases ^b	360–315	228–222	228–218	145–139	

^a Results are based on the subset of cases for whom supplemental information was collected. The parental characteristics refer to the time of the child's death. Results exclude cases with unknown values for each characteristic.

distribution of parents according to selected characteristics of interest for all the parents and for those with different types of involvement with the child with AIDS. The results indicate that the large majority of parents (85%) were aged 50 or over at the time their child died and almost half of these were 60 or older. Consistent with lower female mortality, more mothers were alive than fathers. Most were described as being in good health and three-fourths as average or above average in terms of economic status. The characteristics of parents who co-resided with their child with AIDS are generally similar to the total sample of parents who were alive when their child died of AIDS although the sex distribution is modestly more skewed towards mothers. In contrast, those who provided care differ noticeably in their age and sex distributions from those who did not. Caregiving parents, and especially those who served as main caregivers, tend to be younger than parents of AIDS cases in general. Even so, two-fifths of main caregivers were 60 or older. Caregiving parents and particularly main caregivers are overwhelmingly mothers. Caregivers differ little from the overall sample in their health and economic status distributions.

Table 5 indicates the proportion of parents who coresided with, provided any care to, or were main caregivers for the adult child who died of an AIDS-related disease by the same characteristics of interest

examined in the previous table. ¹³ Close to two-thirds of parents of adult children who died of an AIDS-related disease lived with the child during the illness, a similar proportion provided care, and about half served as a main caregiver. The age of the parent is generally inversely related to co-residence with and caretaking of the ill adult child, with the oldest parents particularly less likely to provide care. The sex of the parent is clearly associated with all three measures of involvement. Mothers are somewhat more likely than fathers to co-reside with an adult child with AIDS and very much more likely to be involved in caretaking. The health status of the parent shows no consistent relation-

^bThe range represents the maximum and minimum number of parents on which results for each set of characteristics are based.

¹³Results are adjusted for the small number of parents for whom information on a particular characteristic is lacking (while sex is known for all, for 11–12% of parents age, health or economic status is lacking). Since cases for whom such information is unknown are skewed heavily towards parents who lived outside the local community and thus were not involved in the living and caretaking arrangements when their child was ill, ignoring them would artificially inflate the indicated levels of involvement for each characteristic category (except sex categories). Thus for the purpose of these calculations, we assume that cases with unknown values of a particular characteristic are distributed similarly to those for whom the characteristic is known. Given the small number of cases involved, this is unlikely to bias results in any meaningful way.

Table 5
Adjusted percent of parents who co-resided with, gave any care, and gave main care to adult children who died of an AIDS-related disease, by selected characteristics of the parent^a

Characteristic of parent	Co-resided	Gave any care	Gave main care
Total	63.3	63.3	40.3
Age			
< 50	70.6	68.0	47.2
50-59	66.8	69.3	46.4
60–69	60.8	61.0	36.1
70 +	50.1	44.4	23.5
Significance level	n.s. ^b	p < 0.05	p < 0.05
Sex		•	•
Father	57.0	45.7	15.2
Mother	67.9	76.1	58.4
Significance level	p < 0.05	p < 0.001	p < 0.001
Health status	_	_	_
Good	64.1	64.5	39.8
Minor probelm	57.5	62.9	48.3
Poor	63.2	54.8	36.3
Significance level	n.s. ^b	n.s. ^b	n.s. ^b
Economic status			
Good	60.3	63.9	36.2
Average	66.5	64.9	41.6
Poor	60.0	60.0	41.3
Significance level ^c	n.s. ^b	n.s. ^b	n.s. ^b
No. of parents	360-315	360-315	360-315

^aResults are based on the parents of the subset of cases for whom supplemental information was collected. The parental characteristics refer to the time of the child's death. Results are adjusted in the sense that parents with unknown values for a particular characteristic are distributed proportionately according to the distribution of parents with known characteristics. Statistical significance is based on parents with known values for each characteristic and measured by the Pearson Chi-square test. Given that the sample is not a probability sample, the levels of significance can only be considered as illustrative.

ship with co-residence, although parents in poor health appear less likely than others to provide care, the overall pattern between health status and the caretaking measures is not consistent. This lack of a clear association between parent's health and caregiving is surprising. The small numbers of parents reported to be in less than good health combined with measurement error due to the subjective nature of the measure may be obscuring the expected positive association.

Discussion

The AIDS epidemic in Thailand clearly has an extensive impact on older people through their involvement in the living and caretaking arrangements of their infected adult children. Two-thirds of adults who died of an AIDS-related disease lived with or next to a parent by the terminal stage of illness and a parent, usually the mother, acted as the main caregiver for about half. Moreover, for 70% of our cases, a parent or other older generation relative provided at least some care. The vast majority of these parents and relatives

were aged 50 or more and many were in their 60s and even 70s.

This high level of parental involvement with adult children who become ill with AIDS contrasts sharply to the situation in the US (and probably other Western countries). According to a 1990 national study, only 13% of AIDS caregivers were 50 or older (17% in central cities) and only 6% at least 60 (Turner et al., 1994). The role of parents in this US study cannot be directly assessed since the relationship of caregivers to the person with AIDS was not asked. The authors infer from the evidence, however, that substantial numbers of caregivers were gay men, a very different modal situation than for Thailand and probably most other developing countries. Another study of caregivers of PWAs based on a sample of unknown representativeness from San Francisco and Los Angeles found that less than 10% were mothers of the PWA (Turner et al., 1998). Separate figures were not provided for fathers but clearly very few were providing care since other family members, the category which presumably includes fathers, represented less than three percent of all caregivers. Almost three-fourths of caregivers in the

^bn.s. = not significant at the 0.05 level.

^cThe range represents the maximum and minimum number of parents on which results for each set of characteristics are based.

study had non-family relationships to the PWAs, most being partners, lovers or friends. ¹⁴

The Thai context differs from the US one in several major respects that could help account for the pronounced contrasts in living and caregiving arrangements. As discussed below, these include less public assistance, the pervasiveness of an informal system of intergenerational support through the later stages of the life course, less stigmatization of the major risk behaviors leading to HIV+ status, and lesser selectivity of those with AIDS with respect to having unstable families of origin or strained relations with their parents.

In developing countries such as Thailand, institutional and other forms of formal care and financial support for persons with AIDS are quite limited compared to the US or Western Europe. Thus persons with AIDS are even more heavily dependent on informal channels of care and support than in the US or other economically advanced settings. In addition, exchanges of services and material assistance between adult children and parents, including co-residence with adult children, constitute a pervasive informal support system for older persons (Knodel et al., 2000). Thus a sizeable minority already live with or next to a parent before becoming ill. Within this system, older parents not only receive help from adult children but also provide important services for them (Knodel et al., 1995). Turning to parents for long term residential care by an adult child is quite congruent with this familial support system.

Numerous discussions of AIDS in the US context have noted the stigmatization of the predominant risk behaviors, namely intravenous drug use and homosexual relations, that underlie the epidemic and the implications that this stigmatization has for the care of patients (Leary & Schreindorfer, 1998). Such stigmatization could well inhibit a person with AIDS from turning to a parent for assistance (Crystal, 1989; Levine-Perkell, 1996; Mullan, 1998). This would be especially likely to be so if the PWA was hesitant to reveal his sexual orientation or drug dependence to his family of origin. In contrast, male commercial sex patronage, the

predominant behavior behind the Thai epidemic, has relatively little social stigma attached to it in Thailand. This is especially so for single men but even under some circumstances for married men (Knodel, VanLandingham, Saengtienchai & Pramualratana, 1996; Knodel, Low, Saengtienchai & Lucas, 1997). More generally, Thai society is noted for its relative tolerance of some forms of sexual behavior that are often viewed very negatively by a significant proportion of society in the US, including prostitution and homosexuality (Jackson, 1995; Peracca, Knodel & Saengtienchai, 1998). This relative tolerance of the risk behaviors underlying AIDS in Thailand, and especially of commercial sex patronage, means that a potentially important barrier to parents' acceptance of an adult child with AIDS in the US is largely absent in Thailand.

While AIDS is still a sensitive matter for many Thai families with an infected member, the extent of social stigma has declined over the course of the epidemic, especially in areas where the disease is most common. In our study, we asked key informants about their general impression of the local community reaction to recent AIDS cases and whether the reaction has changed over time. Many reported that early in the epidemic, there was considerable fear of associating with AIDS cases. However, in 90% of the sites, informants reported that the situation has improved and most claimed that community members now generally did not consider the presence of an AIDS case in the community to be a matter for undue concern. We also asked about specific reactions to individual cases and to their families after their death (for the subset of cases for whom we collected supplementary information). Informants reported some negative reactions to a sizeable minority of the persons with AIDS at the time of illness but only rarely reported any residual stigma towards the family following death. Although the families themselves might have responded less sanguinely than our informants, the general point is that stigmatization, while present, may be less in Thailand than in many other settings (e.g. Sankar et al., 1998). 15 This in turn could facilitate not only the willingness of the PWA to return to the place of

¹⁴One study of 106 PWAs in New Jersey reported results that imply somewhat higher levels of parental involvement (Crystal & Schiller, 1993). According to the study, 40% were living with "parents or other family of origin" and 31% of the 65 respondents who reported a single primary helper indicated it was their mother. However, only about a third of those selected for the study could be interviewed and a large proportion of the non-response was due to "inability to locate". Thus it seems likely that the results seriously overestimate involvement of family members since persons living in stable settings would be far easier to locate and interview than cases living on the streets or in other temporary or unstable non-family arrangements. This could explain much of the apparent discrepancy with the national sample results referred to above which were based on a general sample of households using random digit dialing.

¹⁵As noted in the Data and Methods section, our sample is somewhat skewed towards higher prevalence provinces. It is possible that discrimination effects are less than where the epidemic is less advanced. For example, for the subset of cases about which we asked supplemental questions, the percentage of cases for which negative reactions to the family were reported during the period of illness was lower in the high prevalence upper north (20%) than elsewhere (34%). Likewise, negative reactions to the family after the death were reported for only 3% of the cases in the upper north compared to 12 percent elsewhere. However, as also noted in the Data and Methods section, because of our purposive inclusion of all regions in our sample, lower prevalence areas are well represented.

origin but also acceptance by Thai parents of an adult child with AIDS.

Finally, we speculate that a higher proportion of Americans (and Westerners generally) than Thais who contract AIDS have strained relations with parents or come from families of origin whose circumstances mitigate against their being viable sources of care and assistance. We expect this to be the case because of the different distributions of risk behaviors that are associated with the epidemics in the two settings. The very behaviors that are common among US AIDS cases, namely homosexual relations and IV drug use, are potential sources of strained relations with parents that likely predate the adult child's illness from AIDS (Brabant, 1994). Also, although disputed, IV drug users and their partners in the US may be disproportionately from unstable and otherwise socially and economically disadvantaged family backgrounds (Campbell, 1999; Chatham, Hiller, Rowan-Szal, Joe & Simpson, 1999; Crystal & Glick Schiller, 1993; Fergusson & Horwood, 1999; North, Smith, Pollio & Spitznagel, 1998). Both of these factors would seem likely to make it relatively difficult for a typical American PWA to turn to one's parents for assistance and care in the case of AIDS. 16 In contrast, commercial sex patronage by men in Thailand is relatively common and considered more or less acceptable behavior by broad segments of Thai society (although this may be rapidly changing as a result of the AIDS epidemic). Moreover, Thai women mainly contract HIV through sexual intercourse with their husbands, obviously a completely acceptable and expected marital behavior. Neither of these behaviors is likely in and of itself to cause strains with parents and the persons involved are probably far less selected for difficult family of origin circumstances. Thus Thais with AIDS are less likely to encounter the barriers to turning to parents for care and shelter that likely face many of their Western counterparts.

The Thai situation obviously has aspects that are unique to Thailand. Thus caution must be used in drawing inferences for other countries. Yet in important ways there are broad similarities with many other settings in the developing world, especially when compared to the US or other economically advanced countries of the West. These include the predominance of heterosexual transmission of HIV, a social atmosphere tolerant of transactional sex, the lack of extensive formal

support and services for persons suffering with AIDS, and primary reliance on exchanges between parents and adult children for old-age support including extensive coresidence. We thus expect that the involvement of older persons in the living and caretaking arrangements of persons with AIDS in many other developing countries will be far closer to that revealed for Thailand than typical of the US situation. At least one recent study in Uganda confirms the primacy of parents as caregivers to adults with AIDS (Ntozi & Nakayiwa, 1999). Clearly more attention needs to be given to assessing the extent and nature of how the AIDS epidemic impacts older populations in the developing world as well as the public health and social welfare implications of those impacts for the older persons who are affected.

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¹⁶ Although Crystal and Schiller (1993) argue against the characterization of IV drug users as "disaffiliated" and lacking social ties to their families of origin, they cite numerous studies that support it. They base their objections on results of the New Jersey study cited above that shows substantial percentages of IVDU AIDS cases living with their "consanguineous" family. However, as already noted, the study appears potentially seriously biased towards persons in stable living arrangements.

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