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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 persons and when they do, focus is typically on those who are infected themselves. 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 and examine the parental characteristics associated with them. Interviews with local key informants in the public health system in an extensive sample of 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 AIDS 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 percent, either a parent or other older generation relative provided at least some care. The vast majority of the parents were age 50 or more and many were age 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.

Key words: AIDS, Older Persons, Thailand, Caregiving, Living Arrangements

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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 et al. 1989; Ory et al. 1998a). A far greater number of older persons, however, are affected through the infection of significant others, especially as parents of AIDS victims (Allers 1990; Brabant 1994; Levine-Perkell 1996; Ory and Mack, 1998). Impacts of AIDS on parents can occur through numerous routes including 1) strains of care-giving and associated opportunity costs 2) providing financial and material support 3) raising surviving grand children 4) suffering emotional stress and 5) losing old-age support that the child would have provided (VanLandingham et al. forthcoming). 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 and Sankar 1998; Ellis and Muschkin 1996). Yet few studies focus on older people as parents of persons with AIDS (see however Brabant 1994; Ellis and Muschkin 1996; Levine-Perkell 1996; Mullan 1998; Nazon and Levine-Perkell 1996; Sankar et al., 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. This applicability of this U.S. based literature 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 these existing rarely provide quantitative assessments (see, however, Crystal and Schiller 1993; LeBlanc et al. 1997; Mullan 1998; Turner and Catania 1997; Turner et al. 1994 and 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 et al. 1998b; Sankar et al. 1998; Spira et al. 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 U.S. 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 et al., 1994; Knodel et al, forthcoming; UNAIDS 1998a and b).

The Thai Setting

Recent estimates indicate 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 et al. 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 overall death rate more than doubled between 1990 and 1996 as a result of tens of thousands of excess deaths, presumably attributable to AIDS (van Griensven et al. 1998).

In common with most developing countries, heterosexual intercourse is the overwhelming route of HIV transmission in Thailand (over 80 percent of cases reported through 1998). Intravenous drug use accounts for 5 percent and homosexual/bisexual relations for only 1 percent. 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 and Sittitrai 1995; Brown and Xenos 1994; Ford and Koetsawang 1991).

Intergenerational exchanges of services and material support remain pervasive in Thailand as they do in much of the developing world (World Bank 1994). Widespread norms support filial obligations to parents, including expectations of old age support in the form of remittances and coresidence (Knodel et al. 1995). As recently as 1995, nearly three-quarters of parents aged 60 or above coresided with an adult child and 90 percent either lived with or had daily contact with one. Among persons aged 60 or over with children living outside the

household, 89 percent received food or clothes from them during the prior year, 88% received money, and 69% received significant amounts (defined as \$30 or more). Almost half (49%) reported their children as their main source of support (Knodel et al. forthcoming).

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 in the countries having the highest levels of HIV and AIDS. Thus the findings of the present study have considerable relevance for other developing countries that are also experiencing an increasing burden of AIDS.

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 and occurred primarily during the first half of 1999. To protect confidentiality, names of individual cases were not recorded.

Using this approach, we obtained basic information on living arrangements and care-taking for 1066 cases who were currently ill with or had died of AIDS (including a subset of 285 cases for which the supplemental questions were asked) in 85 sites in 8 provinces and Bangkok. The provincial samples were drawn from all major regions of Thailand and included both rural and urban

sites in each province.¹ 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 1991-98. 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 in 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 also included community leaders, welfare workers, home visiting nurses, and other health personnel.

To keep interview length manageable, we usually limited the number of cases for which basic information was requested to a maximum of 20 per site who died locally of AIDS and 5 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 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. Our quantitative analysis, however, is restricted to the 963 adult cases (including 285 with supplemental information) who either were still present with symptoms (195 cases) or died locally (768 cases).²

A key informant approach carries potential risks. For example, informants might be selective in their familiarity with cases in

ways that could bias results. Also their responses could reflect presumptions 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 low response rates (Levy and 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.

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, namely 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).

With regards to sex distribution, 26 percent of our adult sample are women compared to 23 percent among nationally registered cases reported for 1997-98.³ Thus overall our sample is only modestly more weighted towards women compared to all reported cases.⁴ Figure 1 presents additional comparisons. Panel A shows that the age distribution of persons living with or who died of AIDS 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.⁵

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 parent among the general population as found in 1994 the National Survey of Elderly.⁶ For the purpose of this comparison, our sample results are adjusted

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).⁷ 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.⁸

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 victims 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 and 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.⁹ Some waited until the illness was very advanced. For example, about a third (32%) of those who returned when ill lived only 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.

This link between migration and stage of illness has implications for estimates of the percentages of parents who coreside with AIDS inflicted adult children 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 victims 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. Such an adjustment is necessary since cases for whom the living status of parents is unknown are necessarily selective of those who did not coreside 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.¹⁰

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 AIDS coresided with a parent at the terminal stage. Moreover, two-thirds either coresided or lived next door, reflecting the fact that married children, especially in rural Thailand, often live in the same family compound (Knodel and 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 AIDS 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% a parent was a main caregiver. Even when a parent was not involved, other older generation relatives sometimes played a caregiving role. Thus 70 percent of adult AIDS victims 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 AIDS relate to coresidence 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.¹¹

The unadjusted results for both all cases and cases conditioned on having a living parent show that both coresidence 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 coresidence with a parent but women seem modestly more likely to have a parent as 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 AIDS 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 having a living parent (given that they are considerably older than other cases on average - see following table). Once results are conditioned on availability of a living parent, the tendency to coreside 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 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 AIDS compared to other persons. Results are shown according to the sex and marital status of persons who died of AIDS. 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. 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 an already ill spouse.

The configuration of caregivers varies considerably with the marital status of the person who died of AIDS. 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 percent. Still, even for married AIDS cases, parents are frequently involved as a main care taker and provide at least some care for more than half. 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 caretaking assistance by the spouse who was well. This is suggested by the fact that in over 40 percent 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 AIDS and how they relate to involvement with living and caretaking arrangements is available for subset of cases about which we asked additional questions. Results presented in Table 4 refer to parents who were alive at the time of the child's death. The first four columns show the distribution by the characteristics in question for all the parents and for those with different types of involvement with the AIDS case. The last three columns indicate the proportion of parents in each characteristic category who coresided, provided any care, or were main caregivers respectively.¹²

Focusing first on the distribution of parents by characteristics (the first four columns), we see that the large majority of

parents (85 percent) were age 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 coresided with their AIDS inflicted child 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 female. Caregivers differ little from the overall sample in their health and economic status distributions.

Turning to the proportions of parents involved with adult children who died of AIDS (the last three columns), we see that overall, close to two thirds of parents of adult children who died of AIDS 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 coresidence 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 coreside 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 relationship with coresidence, 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 in 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 AIDS 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 percent of our cases, a parent or other older generation relative provided at least some care. The vast majority of these parents and relatives were age 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 3% of all caregivers. Almost three fourths of caregivers in the study had non-family relationships to the PWAs, most being partners, lovers or friends.¹³

The Thai context differs from that in the US 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 AIDS victims 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 coresidence with adult children, constitute a pervasive informal support system for older persons (Knodel et

al. forthcoming). 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, Saengtienchai and Sittitrai 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. 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, 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 et al. 1996 and 1997). More generally, Thai society is noted for its relative tolerance of some forms of sexual behavior that are often deemed deviant in the US, including prostitution and homosexuality (Jackson 1995; Peracca et al. 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 percent 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).¹⁴ This in turn could facilitate not only the willingness of the PWA to return to the place of 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 et al 1999; Crystal and Schiller 1993; Fergusson and Horwood 1999; North et al. 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.¹⁵ 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 Thai AIDS victims are less likely to confront 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 and 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 implications of those impacts for the older persons who are affected.

Endnotes

¹ The 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.

² 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.

³ This and the following comparisons focus on reported cases for 1997-98 since our sample is skewed towards recent cases reflecting the selection process and the timing of fieldwork.

⁴ The proportion of our sample that consists of currently symptomatic cases, however, is particularly high in its representation of women (43 percent) 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 AIDS because death, as opposed to onset of symptoms, quickly becomes public knowledge regardless of sex.

⁵ In our sample, 42 percent of women living with or who died of AIDS were formerly married compared to 14 percent of men.

⁶ Although, 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.

⁷ In 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 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.

⁸ The expected age distribution of parents of AIDS victims 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.

⁹ 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.

¹⁰ The nature and logic of the adjustment is the same as that described above for panel C of Table 1.

¹¹ 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.

¹² When calculating results for the last three columns for parental characteristic categories, adjustment is made for the small number of parents for whom information on a particular characteristic is lacking (while sex is known for all, for 11-12 percent 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.

¹³ One study of 106 PWAs in New Jersey reported results that imply somewhat higher levels of parental involvement (Crystal and Schiller 1993). According to the study, 40 percent were living with "parents or other family of origin" and 31 percent 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 was based on a general sample of households using random digit dialing.

¹⁴ We have conducted open-ended interviews to collect qualitative information from a small number of parents who have cared for a child afflicted with AIDS and generally the parents in these interviews concur with the impressions of the key informants in this respect.

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

| | Persons who died of AIDS | Persons with symptomatic AIDS |
|---|--------------------------|-------------------------------|
| All Cases | | |
| % coreside with parent when ill | 58.8 (1.8) | 49.0 (3.6) |
| % coreside 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) | | |
| % coreside with parent when ill | 69.7 (1.8) | 60.6 (3.8) |
| % coreside with or live next to 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) |
| Number of cases (a) | 659/645 | 164/162 |

Notes: Standard errors are in parentheses.

(a) The 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.

(b) Estimates are adjusted for cases for which the key informant did not know the living status of the parents. See note in Figure 1.

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

| Demographic characteristic of person who died of AIDS | N of cases(a) | % who lived with a parent when ill | | | | % for whom parent is main caregiver | | | |
|---|---------------|------------------------------------|----------|--------------------|----------|-------------------------------------|----------|--------------------|----------|
| | | All cases | | 1+ parent alive(b) | | All cases | | 1+ parent alive(b) | |
| | | Unad-justed | Adjusted | Unad-justed | Adjusted | Unad-justed | Adjusted | Unad-justed | Adjusted |
| Age | | | (p=.000) | | (p=.000) | | (p=000) | | (p=.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=.533) | | (p=.656) | | (p=.091) | | (p=.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=.000) | | (p=.000) | | (p=.000) | | (p=.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=.000) | | (p=.002) | | (p=.001) | | (p=.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 |

Notes: The 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.

(a) The range represents the maximum and minimum number of cases on which results in each row are based.

(b) Estimates are adjusted for cases for which the key informant did not know the living status of the parents. See note in Figure 1.

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 AIDS

| | Total | Sex | | Marital status | | | |
|--------------------------------|--------|------|--------|----------------|---------------------|---------|-------------------|
| | | Male | Female | Single | Separated /divorced | Widowed | Currently married |
| N of cases (a) | 738(b) | 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 (c) | 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 |

Notes: 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.

(a) Refers 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

(b) Includes 6 cases of unknown marital status.

(c) Estimates are adjusted for cases for which the key informant did not know the living status of the parents. See note in Figure 1.

Table 4. Percentage distribution of parents of adult children who died of AIDS according to selected characteristics of the parent and adjusted percent of parents who coresided with, gave any care, and gave main care to adult children who died of AIDS

| Characteristic of parent | Percentage distribution(a) (totals 100% for each characteristic) | | | | Adjusted(b) percent of parents who | | |
|--------------------------|---|--------------------|--------------------|------------------|------------------------------------|---------------|----------------|
| | All parents | Coresident parents | Providing any care | Main care-givers | Co-resided | Gave any care | Gave main care |
| Total | 100 | 100 | 100 | 100 | 63.3 | 63.3 | 40.3 |
| Age | | | | | | | |
| < 50 | 14.8 | 16.5 | 15.9 | 17.4 | 70.6 | 68.0 | 47.2 |
| 50-59 | 37.2 | 39.3 | 40.7 | 43.1 | 66.8 | 69.3 | 46.4 |
| 60-69 | 37.2 | 35.7 | 35.8 | 33.3 | 60.8 | 61.0 | 36.1 |
| 70+ | 10.7 | 8.5 | 7.5 | 6.3 | 50.1 | 44.4 | 23.5 |
| Significance | -- | -- | -- | -- | n.s. | * | * |
| Sex | | | | | | | |
| Father | 41.9 | 37.7 | 30.3 | 15.9 | 57.0 | 45.7 | 15.2 |
| Mother | 58.1 | 62.3 | 69.7 | 84.1 | 67.9 | 76.1 | 58.4 |
| Significance | -- | -- | -- | -- | * | *** | *** |
| Health status | | | | | | | |
| Good | 79.4 | 80.3 | 80.9 | 78.5 | 64.1 | 64.5 | 39.8 |
| Minor prob. | 9.8 | 9.0 | 9.8 | 11.8 | 57.5 | 62.9 | 48.3 |
| Poor | 10.8 | 10.8 | 9.3 | 9.7 | 63.2 | 54.8 | 36.3 |
| Significance | -- | -- | -- | -- | n.s. | n.s. | n.s. |
| Economic status | | | | | | | |
| Good | 23.2 | 22.1 | 23.4 | 20.9 | 60.3 | 63.9 | 36.2 |
| Average | 50.2 | 52.7 | 51.4 | 51.8 | 66.5 | 64.9 | 41.6 |
| Poor | 26.6 | 25.2 | 25.2 | 27.3 | 60.0 | 60.0 | 41.3 |
| Significance | -- | -- | -- | -- | n.s. | n.s. | n.s. |
| N of cases(c) | 360-315 | 228-222 | 228-218 | 145-139 | 360-315 | 360-315 | 360-315 |

Notes: 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. Statistical significance is based on cases with known values for each parental characteristic and measures 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: n.s. = not significant at the .05 level;

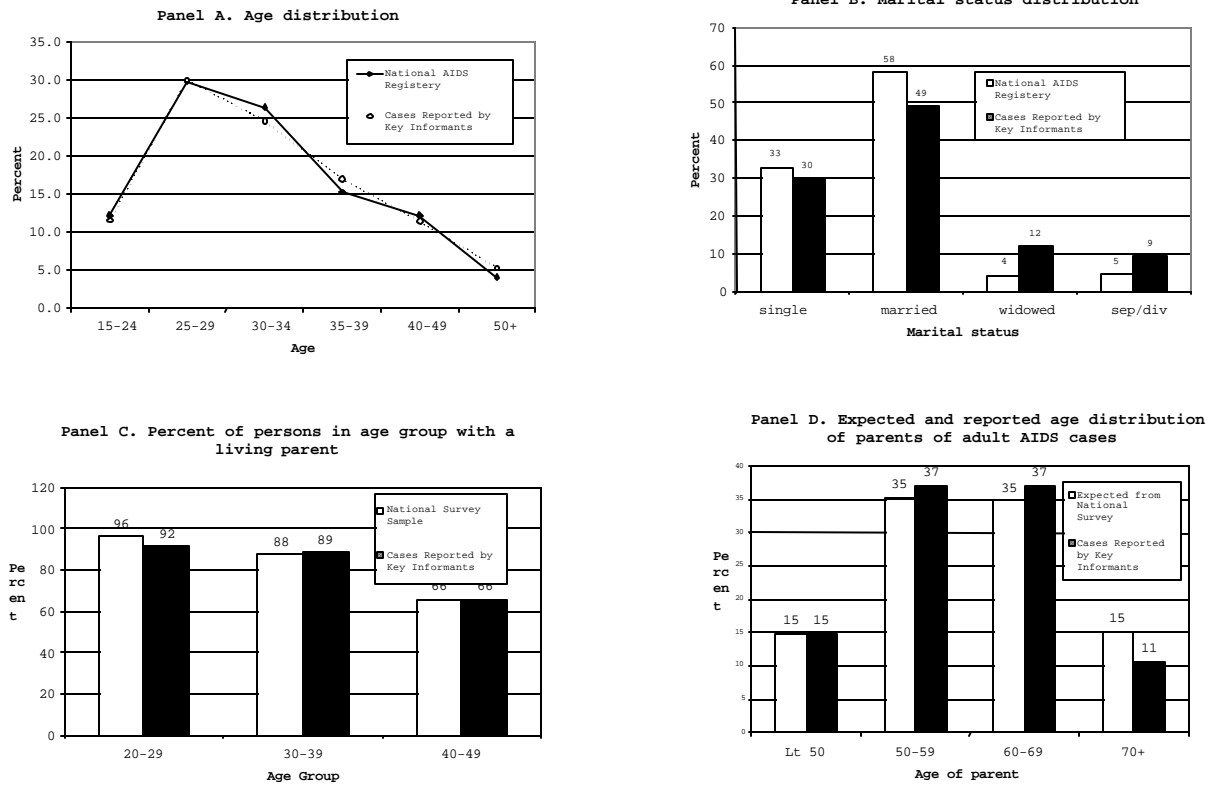
* = $p < .05$; ** = $p < .01$; *** = $p < .001$.

(a) Excludes cases with unknown values for each characteristic.

(b) Cases with unknown values for a particular characteristic are distributed proportionately according to the distribution of cases with known characteristics.

(c) The range represents the maximum and minimum number of cases on which results for each set of characteristics are based.

Figure 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 (Graphs A and B); Original tabulations from Thailand, National Statistical Office, 1994 Survey of Elderly in Thailand (Graphs C and D).

Note: Estimates in Panel C are adjusted for the 8 percent of cases for which the key informant did not know the living status of the parents. The adjustment is made on an age specific basis assuming that the proportion of these cases with a parent alive is 2/3 that of cases in the same 5 year age group where the status of the parents is known. Estimates in panel D compares 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.