S05 Consequences of HIV/AIDS / Conséquences du SIDA

Return Migration in the Context of Parental Assistance in the AIDS Epidemic: The Thai Experience

John Knodel Population Studies Center University of Michigan PO Box 1248 Ann Arbor, MI 48106-1248 USA

(Paper for presentation at the XXIV General Population Conference of the IUSSP, Salvador, Brazil, 18-24 August 2001)

(June 15, 2001)

Abstract

Most persons with AIDS (PWAs) eventually require demanding caregiving. This can prompt changes in living arrangements during the course of the illness. Few studies have attempted to examine the potential links between AIDS and migration from this perspective. The present study uses both direct and indirect approaches to examine the extent of return migration of adults with AIDS in Thailand and explores how this is linked to residence with and care by older aged parents. Methodological challenges to the study of this phenomenon are discussed. Despite differences in the nature of information available from our samples and in basic sample characteristics, the findings show a consistent pattern suggesting extensive return migration among PWAs. Most return migrants die within a few months of their return thus indicating they are seeking parental caregiving and during the final stages of the illness.

Introduction

AIDS is a debilitating and fatal illness that typically leads to dependency on others for caregiving and other forms of support. While persons with AIDS (PWAs) are often able to continue to work and care for themselves initially, most require demanding caregiving during the final stages. Moreover, the virtual certainty of death, at least for most of the infected living in developing countries, and the potential stigmatization associated with the disease are likely to lead PWAs to seek an emotionally supportive environment in which to live after their symptoms become obvious to themselves and others. These aspects of the disease often prompt changes in living and caretaking arrangements during the course of the illness. Only a handful of studies have attempted to examine the potential links between AIDS and migration and residential mobility from this perspective. Moreover, some rely on very indirect evidence such as comparisons of the geographical distribution of HIV diagnoses and AIDS deaths (e.g. Ellis and Muschkin 1996; Buehler et al. 1995; Cohn 1994; Davis, Cameron and Stapleton 1992; Rumley et al. 1991).

In developing country settings where public social services, hospices, and in-patient hospitalization are at most modest for persons with AIDS, they must rely on informal assistance in the form of home care. Those who are married or in a partnered relationship may rely on their spouse or partner as their main source of care and emotional support, although in some cases the very fact of AIDS may create a strain that weakens or dissolves the relationship. Also if the non-ill spouse continues to work, assistance in caregiving is often required. PWAs who are single (or non-partnered) often have no one on whom they can depend for care and support other than their parents, siblings or other close relatives. Thus many who live away from their place of origin at the onset of symptoms may return to their parental home when they can no longer earn a living to support themselves financially or when they need extensive care assistance. In addition, adult children who live separately but in the same locality as their parents may need to move in with their parents if they and anyone else they are living with are unable to cope with the situation on their own.

Previous research in Thailand reveals that the most common place for adult PWAs to spend the terminal stage of the illness is in the parental home and the most common caregiver at this stage is a parent, particularly a mother (Knodel et al. 2001). Two-thirds of adults who died of AIDS either coresided with or lived next door to their parents. For those cases with a parent alive at the time of illness, more than three fourths received some care from a parent and for almost 60 percent a parent was a main caregiver. The vast majority of AIDS parents were at least age 50 and more than half were 60 or over. The importance of parents as caregivers to adult children with AIDS is also likely to be the case in many other settings in the developing world where the epidemic has spread. A series of surveys in Uganda found similar levels of parental involvement as primary care givers (Ntozi and Nakayiwa 1999). Qualitative research in Uganda and anecdotal evidence in Zimbabwe also stress the important role of parents in caring for AIDS-afflicted adult children (Mupedziswa 1997; Williams and Tumwekwase 1999).

The purpose of the present analysis is to examine the extent of return migration of adults with AIDS in Thailand and explore how such movement is linked to residence with and care by older aged parents. As far as we are aware this is the first analysis of this phenomenon, not just for Thailand but for anywhere, that incorporates direct information on migration histories for a sizeable number of cases. The analysis is based on a variety of direct and indirect evidence, most of which has been collected by the authors themselves as part of a comprehensive study on the socio-demographic impact of the AIDS epidemic on older persons in Thailand.

Data and Methods

Several different sources provide data for the analysis: 1) interviews with key informants; 2) a survey of AIDS parents (i.e. parents who had an adult child die from AIDS); 3) questionnaires from PWA group members; and 4) applications for welfare assistance specifically designated for PWAs and their families.

The key informant study yielded information for over 1000 individual cases of persons who were living with or who has died of AIDS.¹ Interviews with local key informants, mainly in the public health system, were conducted in 1999 in 85 sites in rural and urban communities in 8 provinces (including at least one in each of the four major regions of Thailand) and in Bangkok. The informants were asked if the PWA moved back to the community after being ill and, in cases where the PWA lived with a parent, how long during the illness they coresided.² The AIDS parents survey consisted of 394 interviews with parents who lost an adult child to AIDS, mostly within the prior three years. The survey was conducted in 2000 in three provinces, two with high prevalence in the upper north and central regions respectively and one moderate prevalence province in the lower north. The interviews included a series of detailed questions about changes of residence of the adult child since showing signs of illness.

The PWA group member data are derived from self-administered questionnaires filled out in 1999 and 2000 by 425 members of PWA groups in three higher prevalence provinces in northern Thailand and in Bangkok and a neighboring province.³ Welfare applicant information was extracted from 826 applications for welfare assistance specifically designated for PWAs and their families. These applications were submitted between 1996 and 1999 in six of the provinces covered in the key informant survey. Both the PWA questionnaires and the welfare applications provide information on the percent of PWAs who live with older persons (defined as over 50 and over 60) and who live with parents. Comparison with the general population of the same ages regarding these measures permits inferences about the extent to which PWAs change residence to be with a parent or some other older person as a result of illness. We have tabulated age specific data on the general population who live with an older person based both on the 1990 Thai census 2% sample and a large nationally representative 1994 survey conducted by the National Statistical Office. This latter survey also provides age specific information on the percent of the general population living with a parent.

Although all of the above sources of information have limitations and potential biases (discussed below), taken together they provide an unusually comprehensive set of information on the residential mobility of PWAs and permit a far more extensive analysis than any previous study of which we are aware.

Potential Sample Biases

There are serious methodological challenges to obtaining information about residential mobility of persons with AIDS. Random sampling of households to get information about persons who are ill with or who died from AIDS is impractical in most contexts for several reasons. In some cases, the household where the AIDS death occurred may no longer exist. In addition, since in many contexts AIDS is a sensitive topic, illness or death due to AIDS may not be acknowledged as such. Moreover, unless prevalence is very high, the presence of a person with AIDS or the occurrence of an AIDS death in a household is an uncommon event and sampling households randomly would be an impractical way to find cases, especially given the sensitive nature of admitting to AIDS. Indeed, virtually any practical approach to gather information will be prone to some type of bias. Our strategy is to use a variety of different approaches, each of which has its own problems, but which are unlikely to suffer from the same type of biases. To the extent a consistent picture emerges from the findings despite these different biases, it is likely to represent a true pattern rather than being simply an artifact of the data collection methods.

As our analysis below shows, many who eventually return to a parental home often do only when symptoms are advanced and death is imminent. Thus, unless the person with AIDS has already died, the full extent of moves and particularly eventual return moves to a parental home will be underestimated. For this reason, samples of living PWAs, such as from PWA group members or from welfare applicants (as represented through their applications), will underestimate the extent of return to parental homes. In the present study, the extent of this bias is likely greater for the PWA group members than for the welfare applicants since the former are all well enough to attend meetings and fill out questionnaires while the latter can have their application filled out by a proxy and, to qualify for welfare, the PWA is typically required to be certified by a medical doctor as having advanced symptoms.

Neither PWA group members nor welfare applicants are likely to represent a typical cross section of those suffering from AIDS. Welfare applicants are skewed towards the poorest strata of Thai society who may differ in their residential mobility patterns from other PWAs both before and after becoming ill. In addition, although the application includes an item asking for a list of persons with whom the applicant currently lives, the information provided was sometimes missing and even when present on the application might not be accurate. Of particular concern is that the list of current household members might refer to those who are legally registered as residents of the household rather than those who are actually living there at the time of the application. In Thailand everyone is required to be registered in a household and indeed the official household registration form for the household in which the applicant is legally registered had to be submitted with the welfare application. In reality, it is not uncommon for Thais who move out of their household of origin to retain their registration in their former household rather than register in a new household. Thus official household membership as indicated by the registration forms do not necessarily accurately represent currently actual residents. To minimize this problem in the welfare application data, we excluded from our analysis most applications that lacked separate information on the item requesting a list of persons with whom the applicant coresided. In addition, we performed a variety of complex consistency checks between information in the official household registration form (which was attached to the welfare applications) and other information written on the applications (including the list of coresident persons). This permitted us to eliminate most cases in which the information on actual living arrangements was inaccurate. Nevertheless, in this sense, information from the PWA group questionnaires has an advantage over the welfare applications because the PWA group questionnaires were filled out completely independently of official household registration forms.

Obtaining information about persons who died of AIDS obviously must rely on a proxy. In our research we used local health staff both as key informants who provided information themselves about cases in their area and as intermediaries to identify AIDS parents who in turn served as proxy respondents for the their who had died of AIDS. Identifying AIDS parents through intermediaries to ask about return migration, as was done in the AIDS parents survey, risks biasing the sample towards cases where the adult child returned. Since local deaths typically become common knowledge, especially among local health personnel, they are more likely to know of parents whose child died locally (which would include those who returned) than of parents who lived locally but whose child died elsewhere without returning. In contrast, in our key informant study, we asked the health personnel to identify and provide information on persons who died locally, regardless of whether their parents lived locally. This can avoid the aforementioned bias but only if the key informants were aware of all cases who died and the sites picked included a sufficient share of sites to which adults migrate before they become ill, seeking work, for example. It would also be important to include a sufficient number of sending communities.

In the case of our key informant study, is important to consider if our sample design met these conditions. In Thailand, many young adults migrate from their parental home in the provinces to find work in urban centers, especially Bangkok. As noted, Bangkok and other urban places are included as sample sites. Nevertheless, the limited number of cases from these places, the non-random nature of our sampling of sites within urban areas, and potentially selective familiarity on the part of key informants with cases involving native persons could potentially skew our results towards cases who never left and those who returned to their place of origin compared to those who moved in from elsewhere and did not return. If adults who migrated to Bangkok (or elsewhere) and died of AIDS without returning to their parental home before death are substantially under represented in our data, our results would result in overestimating the extent of return migration.

We followed several strategies to assess this problem and they all suggest that the extent of any such bias in the key informant study is likely to be small. First, we interviewed staff of four major organizations who assist large numbers of persons with AIDS in Bangkok. They consistently reported that despite common initial hesitancy on the part of some PWAs to reveal their situation to their parents, most migrants they were aware of eventually returned home, especially once they became too ill to work, even if they were married. 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; some or all of these likely returned to their parental home. Third, when we directly asked provincial-level and local key informants about this matter, almost all agreed that the vast majority of AIDS cases would return to be with their parents before dying.⁴

One distinction between information collected from the PWA group members and from welfare applications compared to information from the key informants study and the AIDS parent survey is that we did not need to rely on intermediaries to identify the cases. Instead cases are self selected. Although neither the PWA group members nor the welfare applicants will be representative of persons with AIDS generally, the biases associated with the self-selection into these groups are likely to be largely independent of the biases associated with identification of persons who died of AIDS by intermediaries.

Problems in calculating return migration probabilities

Ideally direct evidence on return migration to parental homes would be based on a representative sample of persons who start experiencing symptoms from AIDS and follow their mobility through until they die.⁵ This would be true whether the information was collected retrospectively or prospectively. Given information about such a sample on their living arrangements at the time of onset of illness and at death, we could relate the numbers who returned to their parental home during their illness to the appropriate population at risk of doing so (i.e. all those who were not living with a parent when they became symptomatic). We would probably also wish to make these proportions conditional on the availability of a living parent (i.e., restrict the calculations to PWAs who had at least one parent alive at the time of their deaths).

Unfortunately it is difficult to implement such an approach. Both our key informant study and AIDS parents survey provide information on persons who died of AIDS. However, neither provides us with the data needed for appropriate combinations of numerators and denominators to make unbiased calculations of the proportion of PWAs away from their parental home who eventually return, conditional on having a living parent. If the deceased children reported in the sample of AIDS parents were representative of all deceased children of local parents who died of AIDS, regardless of whether or not they returned home, we would be able to calculate unbiased proportions who returned home. However, as already noted, the AIDS parents data almost certainly over-represent parents whose children returned home. Thus the denominator of PWAs at risk of returning home (i.e. the total who were away from parental homes in the sample site when they first became ill including those who did not return) will be too low relative to the numerator (those who did return). Results based on such information will overstate the rate of return migration.

In the key informant study we asked about persons who showed symptoms of AIDS regardless of whether or not they left the community. We also asked about cases of persons whose parents resided locally but who had died elsewhere. Thus theoretically we could calculate proportions who returned to thier parental home in either of two ways. First, we could base the probabilities on a denominator made up of all persons whose onset of symptoms occurred locally but whose parents lived elsewhere and a numerator consisting of those among this group who migrated out to return to their parents before dying. The second would be similar to the case of the AIDS parents sample, namely it would be based on a denominator consisting of deceased children of local parents whose onset of symptoms occurred while they were living elsewhere and the numerator would be those among this group who returned to die in their parental home.

Unfortunately, unbiased calculations of either of these measures are not possible form the key informant data. Both cases who resided locally when first becoming ill but left to die elsewhere and cases whose parents lived locally but died elsewhere are likely to be under-reported relative to persons who died locally. While local deaths are almost always widely known, especially since they are followed by a funeral, becoming ill is a far less salient event in a community and can more easily pass unnoticed than a death by our key informants. Likewise, deaths of adults who died elsewhere but whose parents lived locally are likely unreported since local health personnel would only know about these cases through hearsay orm if the burial occurred locally. Additional problems arise for those whose parental home is not local because in such cases the key informants often did not know where they went or with whom they lived after leaving. Also for a substantial share of persons who were not native to the site, regardless of whether they died of AIDS locally or left and died elsewhere, the key informants did not know if they had a living parent preventing direct calculations of conditional probabilities.

Hence in both the cases of the key informant data and the AIDS parents data, we do calculate probabilities of returning to a parental home among those away at the tine on onset of symptoms. Instead we calculate the proportion who had returned from elsewhere among those died locally. Thus we relate the number who returned to the total number who died locally, a denominator of some interest but not one representing the base population at risk of migrating from which the return migrants came.

Sample Comparability

None of the sources of quantitative data used in the present analysis were designed to be nationally or even locally representative in any statistical sense. Nevertheless, it is instructive to compare them with what would be expected from a nationally representative sample in terms of basic characteristics that are likely to bear on our results. To do this we draw on the national registry of AIDS cases maintained by the Ministry of Public Health. Table 1 shows these comparisons.

[Table 1 about here]

The key informant sample and the deceased children of the AIDS parents are rather similar with regard to their sex distribution to the nationally registered AIDS cases reported for 1997-98.⁶ However, women are clearly over-represented among both the PWA group members and the welfare applicants, but especially the former. Others have noted the predominance of women, primarily AIDS widows, in PWA groups (Muecke 2001). Also some of the welfare programs from which we drew our samples intentionally targeted women. In contrast, the age distributions of PWAs in all four of our samples are rather similar to that of nationally reported AIDS cases. The biggest difference is apparent in the lower proportion of older PWAs among the deceased children reported by the AIDS parents sample, reflecting the lower likelihood that older PWAs have a living parent, a prerequisite to be selected in the sample. The marital status distribution of the key informant sample and the deceased children of the AIDS parents are reasonably consistent with that of nationally reported AIDS cases although there are some discrepancies

in the shares of those who are divorced and widowed. Married persons are clearly the most common followed by single persons in the AIDS registry and both samples. In contrast, the PWA group members and the welfare applicants, especially the former, include far higher proportions of widowed PWAs than nationally is the case. This is related to the disproportionate number of women in the two samples, given that most women become infected though marital sex with their husbands who were infected earlier. Thus the husbands usually die before the wives they infect.

Information on the rural-urban distribution is not available either for the registered AIDS cases or for the welfare cases. However, we note that approximately two thirds of the adult cases reported by the key informants and the PWA group members are drawn from rural settings, thus closely resembling that of the national population in general.⁷ In the case of the AIDS parents, we do not have information on the rural urban distribution of the deceased adult children but 82 percent of the parents were living in rural areas, giving a substantial rural emphasis to the sample.

In brief, these comparisons suggest that the sample of cases reported by the key informants are most similar to the national caseload and the PWA group members the least typical with respect to the combination of characteristics examined. Although together, the four samples provide a wide range of evidence on residential mobility in association with AIDS, these differences in their characteristics, as well as the other potential biases discussed above, need to be considered when interpreting results.

Results

Indirect Indicators

Comparisons between the living arrangements of adults in the general populations represented in the 1990 census and a 1994 nationally representative survey, and the samples of PWA group members and welfare applicants are presented in table 2. The comparisons show that PWAs as represented in either sample are more likely to live with older persons, whether defined as 50 and over or 60 and over, than are persons 20-49 in the in the general population. This is consistent with the suggestion that persons with AIDS change residence when they become ill to live with parents or other older generation relatives. Interestingly, a higher proportion of AIDS welfare applicants live in a household with an older person than do PWA group members. As noted above, AIDS welfare applicants are likely to be at more advanced stages of illness than PWA group members. This difference is consistent with a process involving increased chances of return migration or residential mobility to parental homes as the illness progresses in severity

[Table 2 about here]

Differences in the proportions living with an older person in the general population and among persons with AIDS (as represented by the PWA group members and the AIDS welfare applicants), do not show any consistent pattern associated with age. Also in the case of PWA group members gender is unrelated to the proportions living with an older person. Among AIDS welfare applicants, substantially higher proportions of males who live with older persons than females. We have no explanation for this difference. Both for the PWA group members and AIDS welfare applicants, the tendency to live with an older person is substantially lower if they are currently married than if they are either single or previously married. This could reflect a lesser need for a married person to return to a parental home if a spouse is already acting as a caregiver and source of material support.

Additional comparisons between the 1994 survey of the general population and PWA group members and AIDS applicants with respect to living arrangements is provided in table 3. Here the indicator of living arrangements is the percent who are currently living with or who had lived before death with a parent.

Information is also provided based on the cases reported by key informants. Information from the 1994 household survey is available only with respect to direct coresidence. For PWA group members both direct coresidence (i.e. in the same house) or a broader definition which would include living in the same house or same compound is shown. In the case of the key informant data, cases who are currently symptomatic with AIDS are distinguished from those who had already died.

[Table 3 about here]

In the general population slightly less than a third of persons age 20-49 lived with at least one parent. The percent of persons with AIDS or who had died of AIDS who lived with a parent is higher among AIDS cases as represented in all three data sources. The difference is substantially greater for AIDS welfare applicants than for PWA group members, consistent with the suggestion that the AIDS welfare applicants are at more advanced stage of illness and hence that more would have returned to live with a parent than in the case of the PWA group members. Overall, 60 percent of the cases reported by key informants lived with a parent (not shown), a figure slightly above that for the AIDS welfare applicants. However for those reported to be still living by key informants, the percentage is lower than for those who are reported to have died. Again this suggests a process during which ill adult children return as symptoms worsen.

The percentage of adults who live with a parent in the general population declines sharply with age. This is in part because older adults are less likely to have a living parent but also because over the life course of adult children leave the household to get married or to seek a livelihood elsewhere and thus as they get older fewer are still remaining in their parental household. The decline in the percent living in the same household with a parent among persons with AIDS or who had died of AIDS does not decline as sharply as in the general population. Some decline is apparent, likely reflecting the lower availability of a living parent for the adults in the older age groups. This decline may also be partially influenced by the fact that the proportion who are currently married is probably higher among older than younger adults, at least through the ages of interest here. As the marital status differentials show persons who are married are less likely to be with a parent both in the general population and among the AIDS cases.

Differences between adult sons and daughters with respect to living with a parent are inconsistent among the various samples of persons with AIDS. In the general population, there is very little difference in the proportion of adult men or women who live with a parent. Likewise in the cases reported by the key informants there is only minimal difference between the percent of adult daughters and sons who live with a parent. However in the PWA group members, women are more likely be living with a parent than men while the reverse is true among the AIDS welfare applicants. With the exception of the PWA group members, marital status differentials are consistent in as much as single adults are the most likely to be living with a parent. However as the PWA group data show the marital status differences are moderated if we consider the combined percentage living with or the same compound as parents.

Direct Evidence

Key Informant Study Results

The percent distribution of cases reported by key informants according to return migration status is indicated in table 4 both for currently symptomatic adults in the community and for those who died of AIDS locally. The results indicate that a very substantial proportion of persons with AIDS eventually change residence, often returning to their place of origin. There were also several cases reported but not counted in the results as return migration in which the PWA changed residence locally, typically moving in with parents from a nearby dwelling. When consideration is limited to the subset who were living with or adjacent to parents, the percent who were return migrants is even higher, probably reflecting the

tendency for those to return to do so for the purpose of being with their parents for care and support. Fully two fifths of those who had died of AIDS and were with or adjacent to parents had returned from being elsewhere after they became ill.

[Table 4 about here]

Also of interest is that, both among all cases as well as the subset who were living with or next to a parent, the percent who moved back after becoming ill is noticeably higher among those who died of AIDS than among those still alive. Again this suggests a process whereby adults with AIDS return to their place of origin as the disease gets progressively worse.

Table 5 examines the percentages of adults with AIDS reported by key informants who coresided with a parent and who either coresided or lived adjacent to parents according to return migration status. Among the 37 percent of those who had died of AIDS and had returned to their place of origin after becoming ill, the large majority (77%) moved in with parents or adjacent to them. Moreover, a substantial share (at least half) of those who moved back and did not live with or next to parents had no living parent (results not shown). Some waited until the illness was very advanced. For example, about a third (32%) of those who returned when ill were reported as living 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.

[Table 5 about here]

Table 6 shows the percent who are return migrants among persons who died of AIDS according to age, sex, marital status and place of residence at the time of death of the PWA based on reports from the key informants. 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.⁸ Overall the adjusted results do not differ greatly from the unadjusted results.

[Table 6 about here]

Because the results in table 6 are not probabilities of return migration, as explained earlier, interpretation is not straightforward and can be at best only tentative. In general, the pattern with regards to age is irregular. The highest percent of return migrants is found among those in the 20-24 age group. One possible explanation for this is that those who are in the youngest age group are least likely to be married or to have built up sufficiently intimate relationships in places to which they migrated with persons who could serve as caregivers. However, even after controlling for marital status, this youngest age group still stands out as having the highest proportion of return migrants among them. There is little difference between men and women with respect to the percent who had returned when ill. With respect to marital status, the least likely to return are those who are widowed while the most likely are those who were divorced or separated.

AIDS parents survey results

Results based on the AIDS parents survey are presented in Table 7. A very high percentage of deceased children who died of AIDS are reported as coresiding with or living adjacent to their parents. As noted above, this is undoubtedly an overestimate since the local intermediaries who identified the AIDS parents were less likely to aware of cases in which the a child of local parents died elsewhere than cases in which the child died locally. However, a previous analysis of the key informant data indicated that among

adults who die of AIDS in Thailand and have a living parent, the proportion who live with or next to parents by the terminal stage of their illness could approach 80 percent (Knodel et al. 2001). Also similar to the previous analysis of the key informant survey results, the AIDS parents survey finds that there is not much difference between deceased sons and daughters in this respect. Married children are less likely than other deceased children to have coresided or lived next to parents at the time of death. This could reflect less need to do so if the surviving spouse was acting as a primary caretaker.

[Table 7 about here]

Two measures of return migration are shown based on the AIDS parents survey. Both are expressed as a percent of deceased children who were living with or adjacent to their parents at the terminal stage of AIDS. The first indicates that just over a third (35.4 percent) had moved back within the last two years (whether or not AIDS symptoms had already appeared) and the second indicates just under a third (31.5 percent) moved back after the onset of symptoms (regardless of how long ago they appeared). Although substantial, these figures are somewhat lower than the equivalent figures from the key informant study (see table 4). Gender and marital status difference are only partially consistent with those from the key informant survey (as represented in table 6). It is difficult to account for differences between the findings from theses two sources given the nature of the measure of return migration and the differences in the sample sites and methodologies involved in the data collection.

The AIDS parents survey also provides information on how long children who returned when ill lived with or next to parents before dying. Clearly many adult children who returned were at advanced stages of illness. Overall half died within less than three months of return and over a fifth died in less than a month. While exact comparisons with the key informant information are not possible, the general pictures they present are fairly similar on this account.

Conclusions

There are many difficult methodological problems facing studies of migration of persons with AIDS and even more so if the connection between migration and parental assistance is a focus of the study. The present analysis utilized both indirect and direct information on migration of persons with AIDS in Thailand. While there are problems with each of the approaches used, they nevertheless all point to very substantial return migration to parental homes among persons ill with AIDS. Such high return migration 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. The evidence presented makes clear that much of the return migration takes place only once the severity of illness experienced by a PWA is substantial. Thus studies of the extent of involvement of parents in caregiving, providing shelter or other forms of assistance will underestimate this involvement if based on persons who are currently ill with AIDS. Only by examining the experiences of cases who have already died of AIDS will the full extent of parental involvement be evident.

Acknowledgements: Financial support for this study was provided by the National Institutes of Aging as part of the project "Socio-demographic Impact of AIDS on Older Persons" (grant AG15983). The research was carried out jointly by the Populations Studies, University of Michigan (USA) and the Institute for Population and Social Research, Mahidol University (Thailand). Guidance and assistance was provided throughout the research process by my co-investigators, Chanpen Saengtienchai, Wassana Im-em, and Mark VanLandingham. Mark VanLandingham also provided extensive comments on an earlier draft of this report.

Endnotes

¹ The present analysis is based on the 960 cases who either were currently ill with AIDS in the locality or who had died locally.

² For details of the methodology of the key informant study see Knodel et al. 2000.

³ For details of the methodology of PWA group member study see VanLandingham and Im-em, forthcoming.

⁴ 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 sites, only one case was known. Of course, cases of non-return by their very nature may not be known to the key informant. Still all the evidence we have, along with the generally free flow of information that typifies most rural communities in Thailand, leads us to believe this is a rare event.

⁵ If learning of being HIV positive prior to becoming symptomatic is sufficient to prompt migration, they it would be necessary to start with all who either learn of an HIV positive diagnosis or who become ill.

⁶ We focus on reported cases for 1997-98 since our samples are skewed towards recent cases reflecting the selection process and the timing of fieldwork.

⁷ Exact comparisons with official statistics can not 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 percent of the population was rural and 30 percent were either in officially designated municipal areas or sanitary districts (essentially peri-urban areas).

⁸ 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.

References

Buehler, James, Robert Frey, Susan Chu, and the AIDS Mortality project Group. 1995. The Migration of Persons with AIDS: Data from 12 States, 1985 to 1992. *American Journal of Public Health* 85(11): 1552-1555.

Cohn, Susan et al. 1994. The geography of AIDS: Patterns of Urban and Rural Migration. *Southern Medical Journal* 87(6): 599-606.

Davis, K.A., B. Cameron, and J.T. Stapleton. 1992. The impact of HIV patient migration to rural areas. *AIDS Patient Care* 6:225-8.

Ellis, Mark and Clara Muschkin. 1996. Migration of persons with AIDS- A search for support from elderly parents? *Social Science and Medicine* 43(7): 1109-1118.

Knodel, John, Chanpen Saengtienchai, Wassana Im-em and Mark VanLandingham. (2000). The Impact Of Thailand's Aids Epidemic On Older Persons: Quantitative Evidence From A Survey Of Key Informants. Publication No. 252, Institute for Population and Social Research, Mahidol University, Thailand.

Knodel, John, Mark VanLandingham, Chanpen Saengtienchai and Wassana Im-em. (2001). Older People and AIDS: Quantitative Evidence of the Impact in Thailand, *Social Science and Medicine* 52(9):1313-1327

Muecke, Marjorie. 2001. Women's work: volunteer AIDS caregiving in Northern Thailand. *Women and Health* 33(1/2): 21-37.

Mupedziswa, R. 1997. AIDS and older Zimbabweans: who will care for the carers? *South African Journal of Gerontology* 6(2): 9-12.

Rumley, R.L., N.C. Shappley, L.E. Waiver, and J.D. Esinhart. 1991. AIDS in rural eastern North Carolina -- patient migration: a rural burden. *AIDS* 5:1373-8.

VanLandingham, Mark, and Wassana Im-em. Forthcoming. Living with HIV/AIDS: Results from a Self-Administered Survey. Research report.

Williams Alun and Grace Tumwekwase. Forthcoming. "We will be alone when we die": HIV/AIDS and the aged in rural Uganda. *Journal of Cross cultural Gerontology*.

	Nationally	Total key	Deceased	PWA group	Welfare
Percentage distribution	recorded	informant	children from	member	applicant
by	HIV+ cases	sample of	AIDS parents	sample	sample
	1998/1999	cases	survey	_	_
Sex					
Male	77.0	73.9	79.8	33.3	53.0
Female	23.0	26.1	20.2	66.7	47.0
Total	100	100	100	100	100
Age					
20-24	11.4	11.4	9.6	10.0	13.6
25-29	30.1	30.1	33.2	30.9	29.7
30-34	26.6	24.7	33.4	27.9	29.9
35-39	15.5	17.1	15.5	15.9	15.5
40+	16.4	16.8	8.3	15.2	11.4
Total	100	100	100	100	100
Marital status(a)					
Single	33.0	29.9	29.4	12.5	23.0
Married	59.0	49.2	45.7	28.2	39.1
Divorced/					
separated	4.3	9.1	12.9	13.2	8.5
Widowed	4.6	11.8	11.9	46.1	28.9
Total	100	100	100	100	100
N of cases (b)		960	394	408	826

Table 1. Comparison of age, sex and marital status among nationally recorded adult HIV+ cases and samples from key informants, PWA group members, and welfare applicants

Note: a) the marital status distribution for the nationally recorded HIV+ cases 1998/1999 are from special tabulations provided on request to the Ministry of Public Health. The marital status distributions from this source and from the survey of AIDS parents include ages 15-19.

b) Includes cases with missing values on some variables.

	% living	% living with a person 50+			% living	% living with a person 60+			
	1990	1994	PWA	AIDS	1990	1994 NSO	PWA	AIDS Welfare	
	census	general	group	Welfare	census	elderly	group	applicants	
		household	members	applicants		survey	members		
		sample							
Total 20-49	38.8	39.7	48.0	55.4	21.5	24.5	33.3	37.5	
Age									
20-24	53.2	51.4	56.1	42.0	22.8	26.1	26.8	21.4	
25-29	45.3	49.2	46.8	60.3	23.8	28.0	27.0	32.6	
30-34	34.4	37.1	52.6	57.0	23.5	26.8	36.8	40.6	
35-39	26.9	27.2	44.6	60.5	21.1	23.2	47.7	52.4	
40-44	26.7	26.5	39.5	45.0	17.9	20.5	30.8	41.7	
45-49	36.8	32.8	33.3	(52.6)	15.1	16.6	16.7	(42.1)	
Sex									
male	37.2	38.7	46.5	64.5	21.2	24.1	34.9	43.4	
Female	40.4	40.6	48.7	45.6	21.7	25.0	32.5	31.0	
Marital status									
Single	66.5	63.6	56.3	81.5	34.3	37.3	41.7	55.1	
Married	29.4	31.9	34.2	39.8	16.7	20.0	21.1	26.9	
Divorced/									
Separated	49.2	54.1	53.8	68.8	31.3	40.1	34.6	43.8	
Widowed	27.2	30.8	52.8	47.2	20.1	25.8	38.3	30.5	

Table 2. Percentage of persons 20-49 who live with someone 50+/60+: comparison of general population and AIDS welfare applicants

Source: The general household sample is from the 1994 NSO Survey of Elderly in Thailand. Both the 1990 census and the 1994 household results are from original tabulations.

() = less than 20 cases

	% living with a parent (currently or at time of death)							
	1994 general	PWA group members		AIDS welfare	Cases reported by key informants			
	household sample	in same house	in same house/ compound	appli- cants	Currently sympto- matic	Already died		
Total 20-49	31.3	38.3	48.4	56.0	51.9	61.7		
Age								
20-24	61.2	48.8	51.2	59.8	61.3	71.1		
25-29	38.7	42.9	51.6	62.0	61.7	70.8		
30-34	24.1	36.8	51.8	56.2	46.9	62.0		
35-39	15.8	38.5	52.3	54.0	48.0	59.9		
40-44	12.6	25.6	30.8	35.0	(28.6)	40.7		
45-49	8.2	(8.3)	(8.3)	47.4	**	20.6		
Sex								
male	30.7	32.6	43.4	64.8	53.2	62.6		
female	31.8	41.0	50.8	47.1	50.0	58.7		
Marital status								
Single	76.3	43.8	43.8	86.0	80.5	80.9		
Married	16.4	22.8	39.5	36.1	37.7	46.2		
Divorced/								
separated	55.3	36.5	40.4	68.8	50.0	72.4		
Widowed	25.8	47.0	57.4	50.5	54.3	63.5		

Table 3. Percent living with a parent, by age sex, and marital status among general population and AIDS cases, aged 15-49

Source: Results for the general household sample is from the 1994 NSO Survey of Elderly in Thailand and are original tabulations.

** = less than 10 cases

() = 10-19 cases

		alive with	Persons who died of		
		matic AIDS in the	AIDS in the community		
Migration status	commu	nity			
	All	All Those living		Those living	
		with or adjacent		with or adjacent	
		to a parent at the		to a parent at the	
		terminal stage		terminal stage	
Moved back after becoming ill	25.9	31.4	36.7	40.8	
Moved back within two years					
but before showing symptoms	7.2	7.8	2.7	3.3	
In community during last					
2 years	66.9	60.8	60.6	55.9	
Total percent	100	100	100	100	
Total N	166	102	660	660	

Table 4. Percent distribution of adult persons living with AIDS and those who died of AIDS according to their return migration status

Source: Key Informant Study Note: Adult is defined as age 20 or over

Living arrangement measure and migration status	• •	e with AIDS in the	Persons who died of AIDS in the community		
	community				
	%	N	%	N	
% coresiding with parents during illness					
Returned after ill	69.8	43	71.4	238	
Returned before ill	66.7	12	66.7	18	
Non-migrant	49.1	110	56.1	394	
Total excluding cases with unknown					
migration status	55.8	165	62.0	650	
Total all cases	49.2	193	58.6	752	
% coresiding or living adjacent to parents					
during illness					
Returned after ill	74.4	43	76.9	238	
Returned before ill	66.7	12	83.3	18	
Non-migrant	56.4	110	63.7	394	
Total excluding cases with unknown					
migration status	61.8	165	69.1	650	
Total all cases	57.0	193	66.4	752	

Table 5. Percent of adult PWAs and PDAs who lived with parents during illness by return migration status and living status

Source: Key Informant Study Note: Adult is defined as age 20 or over

	Percent	moving back	N of cases
	unadjusted	adjusted	
Total 20 and above	36.7	36.7	660
Age		(p=.042)	
20-24	50.7	48.5	69
25-29	33.0	32.0	203
30-34	40.1	40.0	157
35-39	37.2	37.7	121
40+	29.0	31.9	110
Sex		(p=.532)	
Male	36.3	36.0	504
Female	37.8	39.1	156
Marital status		(p=.065)	
Single	39.9	38.2	218
Married	34.7	33.3	317
Div/sep	50.0	48.4	58
Widowed	23.4	23.6	64
Residence (at time of death)		(p=.000)	
Rural	41.2	40.8	442
Urban	27.5	28.2	218

Table 6. Percent moving back after onset of symptoms among persons who died of AIDS by age, sex and marital status, unadjusted and adjusted by logistic regression

Source: Key Informant Study

Note: Adult is defined as age 20 or over. 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.

	Characteristic of adult child who died of AIDS					
	All	Son	Daughter	Single	Married	Separated,
						divorced,
						widowed
% who coresided with or lived adjacent to						
the respondent at the terminal stage of						
AIDS	89.1	88.1	92.8	94.0	83.2	92.8
Of those who coresided with or lived						
adjacent to the respondent at the terminal						
stage						
% who moved during last two years	35.4	35.1	36.6	21.6	38.9	44.4
% who moved after onset of symptoms	31.5	29.9	37.3	16.4	38.3	36.9
Of those who moved after onset of						
symptoms to coreside with or live adjacent						
to the respondent						
% who died less than a month after move	22.8	26.7	10.7	(41.2)	24.1	12.8
% who died less than 3 months after move	50.1	59.3	25.0	(58.8)	62.1	30.8
median length of residence before dying	2.4	2.0	5.5	(1.0)	1.8	8.0

Table 7. Residence and residential mobility among persons who died of AIDS as reported by AIDS parents

Source: Survey of AIDS parents

() = 10-19 cases