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

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Return Migration in the Context of Parental Assistance in the AIDS Epidemic:

The Thai Experience

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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 suggestive of extensive return migration among PWAs. The fact that most return migrants die within a few months of their return indicates that they are seeking parental caregiving during the final stages of the illness. The vast majority of PWAs who returned home after becoming ill did so because of their illness, particularly due to a need for care.

Keywords: AIDS; Migration; Thailand; Caregiving; Parental assistance

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 infected persons 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 caregiving 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. While a few of these studies benefit from fairly detailed and up-to-date registries of AIDS patients and AIDS deaths that are sometimes available in developed countries, others rely on very indirect evidence such as comparisons of the geographical distribution of HIV diagnoses and AIDS deaths (Ellis and Muschkin 1996; Buehler et al. 1995; Cohn 1994; Davis, Cameron and Stapleton 1992; Rumley et al. 1991).

The developing country context differs markedly from that of more wealthy countries. Treatments of HIV and opportunistic infections have not been extensively implemented. This has implications for information about the experience and problems of PWAs and their families. Fewer treatments means fewer incentives for AIDS testing, for disclosure of HIV status, and for AIDS patients to provide information to registries. Most significantly for the purposes of this paper, public social services, hospices, and in-patient hospitalization are at most modest for persons with AIDS and thus 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 are likely to return to their family 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.

The present analysis examines the extent of return migration of adults with AIDS in Thailand and explores 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 (together with their Thai collaborators) as part of a comprehensive study on the socio-demographic impact of the AIDS epidemic on older persons in Thailand.

Background

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. Parents are also likely to be important as caregivers to adult children with AIDS 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). Likewise studies in Uganda

and in Zimbabwe also stress the important role of parents in caring for AIDS-afflicted adult children (Mupedziswa 1997; Williams and Tumwekwase 1999; WHO 2001).

These emerging findings about care taking arrangements of PWAs in developing countries has yet to be integrated with existing bodies of knowledge on residential arrangements and population movements. Coresidence between young and older generations is common in Thailand as is migration away from the parental home among young adults for work and educational opportunities (Goldstein and Goldstein 1986; Knodel and Saengtienchai 1996; Knodel, Chayovan et al. 2000; Richter et al. 1997). But we do not know how these long standing residential and migration practices influence or are affected by widespread infection of HIV in the young adult population.

Data and Methods

Several different sources provide data on persons with AIDS 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 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 involved 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 east coast 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. The 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 (no date). 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 a comprehensive set of information on the residential mobility of PWAs and permit a far more extensive analysis than any previous study.

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, 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 so 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. Indeed the official 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 does not necessarily accurately represent current 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 lived. 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, we expect that the AIDS welfare sample probably modestly overstates the percentage of cases who live in households with older persons, including parents. This problem is unlikely to influence information from the PWA group members since they filled out their questionnaires completely independently of official household registration forms.

Information about persons who died of AIDS must rely on proxy reports. 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 provided information for their deceased children. 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 avoids much of the aforementioned bias since these key informants were generally well informed about AIDS deaths in their areas and because our sample includes varied settings representing both typical areas of origin and destination for internal migrants in Thailand. As noted, rural communities as well as Bangkok and provincial cities, the typical destinations of young rural migrants, are included as sample sites (Fuller, Lightfoot and Kamnuansilpa 1990).

Nevertheless, the non-random sampling of sites within urban areas and potentially selective familiarity on the part of key informants with natives to the area could potentially skew our results against 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 overestimate 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.

One distinction between information collected from the PWA group members and 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 and are largely limited to persons who are willing to be relatively open about their HIV/AIDS status. 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. While some cases that are strongly motivated to remain secret may be missed even by the sample identified by our intermediaries, given the general free flow of information in Thai communities, especially rural ones, this number is likely to be very small. Many persons suffering the distinct and severe symptoms associated with AIDS eventually become known to the health staff in the local area because of their need for treatment and referral. Even those who do not contact health officials will ultimately come to their attention through their death. Moreover, the public nature of most funerals in Thailand makes it very difficult for families to hide the circumstances from others in the community. At the same time, the PWA survey provides information that is obtained directly from the PWA himself or herself and includes many PWAs who are living away from home. Both the PWA and the welfare data provide information on cases that are currently experiencing early stages of illness which can be contrasted with information from our other sources that collect data at later stages of illness.

Problems in Calculating Return Migration Probabilities

Ideally direct evidence on the extent of return migration to parental homes would be based on a representative sample of persons who start experiencing symptoms from AIDS while not living with parents and follow their mobility through until they die.⁴ This would be true whether the information was collected retrospectively or prospectively. Given information on the 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). Estimates of return migration could be made separately for all PWAs and for those 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 adult 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 their parental homes 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 their 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 from the key informant data. Both the cases who resided locally when first becoming ill but left to die elsewhere and the 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 by our key informants than a death. 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 or if the funeral 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 these persons 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 not calculate probabilities of returning to a parental home among those away at the time on onset of symptoms. Instead we calculate the proportion who had returned from elsewhere among all those who died locally. While this denominator is of some interest in does not represent 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. Such a comparison reveals the extent to which our nonrandom sample differs from the population of interest on key variables of interest. To do this we draw on the national registry of AIDS cases maintained by the Ministry of Public Health and based primarily on cases that are diagnosed at government hospitals. While this registry is likely to selectively omit cases that are motivated not to be included, these are the only national data of direct relevance to our sample. 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 1997-98.⁵ 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 through marital sex with their husbands who were infected earlier and who usually first.

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.⁶ 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 registry of AIDS cases with respect to their age, sex, and marital status distributions and the PWA group members the least similar. 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

Table 2 compares the living arrangements of adults in the general populations with those of persons with AIDS from our various sources of information. Both the percentage living with at least one older person (defined as someone aged 50 or over) and the percentage living with a parent are shown. Given that most persons with AIDS are in their 20s and 30s, their parents are typically age 50 or over. Household members 50 and older, however, also include other older aged relatives who potentially could be involved in caregiving and support of the younger adult with AIDS. Information on living arrangements for the general population is available from the 1990 census 2% sample only for the percentage living with an older persons while the 1994 general household survey provides information for both measures. Equivalent information is shown for persons with AIDS (or who had died of AIDS), when available, based on PWA group members, AIDS welfare applicants, and cases reported by the key informants. Since the data from the various sources differ in their age and sex distributions, results standardized for age and sex are presented in addition to the unstandardized results. The age distribution of AIDS cases for the years 1997-1999 as reported in the national AIDS registry is used as the basis for standardization.⁷

[Table 2 about here]

The top panel indicates the percent who coreside in the same household (and presumably the same dwelling) with either an older person or a parent. As would be expected, the census and the nationally representative general household sample agree closely as to the percentage of adults 20-49 that reside with an older person. The remaining results in the top panel reveal that the AIDS cases from each of the sources are clearly more likely to live in the same household with an older persons or with a parent

than are persons 20-49 in the general population. This is apparent in both the unstandardized and standardized results and is consistent with the suggestion that persons with AIDS change residence when they become ill to live with older generation relatives and particularly parents. Moreover, the pattern of differences among the various samples of AIDS cases is also consistent with this hypothesized process of return migration. As noted above, PWA group members are likely to be at earlier stages of illness than AIDS welfare applicants while those who died of AIDS already passed through the terminal stage. Thus the fact that higher proportions of AIDS welfare applicants than PWA group members live in a household with an older person and live in a household with a parent, likely reflects an increase in return to parental homes as the illness progresses in severity (although as noted above the welfare data may be modestly biased towards overstating these measures of coresidence). Further evidence of this return migration process is provided by the cases reported in the key informant study. As would be expected, those who died of AIDS not only are characterized by higher proportions living with parents (at the time of death) than those reported as currently symptomatic by the key informants but coresidence with parents at the time of death among those who died is also the highest of all groups studied.

While the top panel of table 2 refers to the percentages of adult AIDS cases living in the same household as a parent, the bottom panel shows the percentage who either coreside in the same household or live in the same compound (or an adjacent dwelling) as a parent. It is not uncommon in Thailand for adult children, especially married children in rural areas, to set up residence next to parents in a separate dwelling (Knodel and Chayovan 1997). This broader indicator of living arrangements, which is available for both PWA group members and cases reported by key informants, has two advantages. First, it captures situations that may not differ significantly from each other in terms of implications for parental caregiving opportunities. Second, it minimizes effects of potential ambiguities in the responses of PWA group members and the key informants that could have arisen from possible confusion over what we meant by "living with parents" in our questioning. Some respondents may have thought of "living with parents" in these broader terms (as opposed to just literal coresidence in the same dwelling) while others may not have. Combining literal coresidence and adjacent living into a single measure eliminates this possible problem. In any event, the pattern of the results in the bottom panel of table 2 is quite consistent with the expectations that the chances of return migration increase with the stage of illness. Both unstandardized and standardized results indicate that among our samples where the necessary information was available, the PWA group members are least likely to live with a parent, persons who died of AIDS were most likely to have lived with parents at the time of death, and those currently symptomatic are intermediate in this respect.

Direct Evidence

Key Informant Study Results

The percent distribution of local cases reported by key informants according to return migration status is indicated in table 3 both for currently symptomatic adults in the community and for those who died of AIDS locally. The results strongly suggest 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 who 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 3 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 4 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).⁸ Some waited until the illness was very advanced. For example, the key informants reported that about a third (32%) of those who returned when ill lived no longer than a few months, including some who died after just a few weeks or even a few days following their return (results not shown). In contrast, rarely were cases reported to have left their place of origin to die elsewhere (results not shown).

[Table 4 about here]

Table 5 shows the percent who are return migrants among persons who died of AIDS according to gender 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.⁹ Overall the adjusted results do not differ greatly from the unadjusted results.

[Table 5 about here]

Interpretation of table 5 can be only tentative because, as explained earlier, the results are not probabilities of return migration, and are influenced by the relative numbers of sons and daughters and of adult children from rural and urban sites who moved away and became HIV affected (information that remains unknown). Nevertheless the fact that there is little difference between men and women in the percent who are return migrants among those who died locally is suggestive of the lack of a strong gender differences in return migration. Also of interest is the substantially higher proportion of return migrants among adults dying of AIDS in rural than urban sites. This is consistent with what might be expected if out-migration among young adults is more likely from rural than urban places, a pattern that is common in most developing countries where opportunities for employment are concentrated in the urban sector.

AIDS Parents Survey Results

The most detailed (and probably reliable) accounts of return migration are provided by AIDS parents themselves. The AIDS parents survey included a number of questions about the nature of and reasons for residential moves made by adult children who died of AIDS following the onset of symptoms. Results are presented in Table 6. A very high overall 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 be aware of cases in which a child of local parents died elsewhere than cases in which the child died locally. However, previous analysis of the key informant data indicated that among adults who died of AIDS in Thailand and had a living parent, the proportion who lived with or next to parents by the terminal stage of their illness could approach 80 percent (Knodel et al. 2001).

[Table 6 about here]

Three measures of return migration are shown in the second panel of table 6 based on the AIDS parents survey. All 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 35 percent had moved back within the last two years (whether or not AIDS symptoms had already appeared); the second indicates that almost a third (31.5%) moved back after the onset of symptoms; and the third indicates that 28 percent moved back because of the illness. Although substantial, these figures are somewhat lower than the levels suggested by the key informant study (for example, key informants reported that 41 percent of adult children who died when residing with or adjacent to a parent had returned home after becoming ill -- see table 3). As with the key informant data, the first and third measures from the AIDS parents survey show little gender difference. However, some gender difference is evident for the second measure, i.e. the percent who returned home after the onset of symptoms.

AIDS parents were asked if the returning adult child with AIDS returned alone or with other family members. As the third panel of table 6 shows, among those who returned after the onset of symptoms, less than half (45 %) came back alone and about a third returned with a spouse and just over a fifth brought children along. Some of these additional family members likely assisted in caregiving while others, especially children, likely added to the economic burden of the older age parents to whom the person with AIDS was returning (Saengtienchai and Knodel 2001).

The AIDS parents survey also provides information on how long children who returned when ill lived with or next to parents before dying (see fourth panel of table 6). Clearly many adult children who returned were at advanced stages of illness. Overall half died within less than three months of return and almost a fifth died in less than a month. This short interval between return and death is especially pronounced among sons, who may have a weaker link with the household than daughters. While exact comparisons with the key informant information are not possible, the general pictures they present are fairly similar on this account.

The AIDS parents were also asked about the reasons that their ill child moved if the move occurred after the onset of symptoms. Respondents were permitted to provide more than one reason. The bottom panel of table 6 shows the percent of those who moved back to live with or adjacent to parents who mentioned particular reasons. By far the most common reason mentioned was the need for care. This finding implies that many who returned did so at an advanced stage of illness when symptoms required assistance from others and is consistent with the short periods between return and death. Indeed, almost one fifth of returning sons were said to have come home to die, although this was a far less common reason stated for daughters. The lack of ability to support oneself also appears to figure prominently for a substantial share of those who returned. The dominance of the need for care followed by need of material support corresponds closely with the reasons stated by PWA group members who were living with or adjacent to a parent and who had said they moved to live with parents due to their HIV/AIDS status. Help with child care was also cited by about half of the PWA returnees who had children (PWA results not shown).

Conclusions

Many difficult methodological problems face studies of migration of persons with AIDS, particularly if the connection between migration and parental assistance is a focus of the study. While there are significant shortcomings with both the indirect and direct approaches used in the present study, taken together they are superior to any single methodology that is conceivable given the realities of AIDS and migration behavior. Perhaps more importantly, the findings consistently point to substantial return migration to parental homes among persons ill with AIDS. Such high return migration is quite understandable 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 symptoms of illness become severe. Cases who have already died of AIDS, and thus for whom the most complete information is available, show the highest proportions living in or adjacent to parental households. Cases who are still alive and at fairly early stages show the lowest rates of return. Quite likely many PWAs postpone as long as possible making a decision to return to parents and only do so when forced by circumstances. Thus for many the return is likely to occur suddenly, with little advance warning to the older parents, and at an advanced stage of illness when the PWA will have pronounced needs.

Such widespread return of PWAs to parents during late stages of illness would be missed by studies relying solely upon truncated PWA histories (i.e. for those who are still alive) and especially if they refer to persons at an early stage of illness. Only the histories of persons who already died of AIDS can reveal the full extent of parental involvement. Our use of a variety of data sources that focus on several stages of the disease provides fairly convincing evidence of this progressive migration process during the course of the illness. The consistency of results we obtain from a broad range of information provides strong evidence that migration of persons with AIDS back to their parental homes is a widespread phenomenon with likely consequential implications for older parents.

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, Saengtienchai et al. 2000.

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

⁴ 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.

⁵ 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.

⁶ 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).

⁷ The standardization procedure simply recalculates the overall percentages by weighting the age-sex specific percentages by the percent distribution according to age and sex of AIDS cases within the 20-49 age range as reported in the national registry. It imposes the same age-sex distribution on all sources and thus permits interpretation of differences in the percentages living with an older person or living with a parent independent of the influence of differences in the actual age-sex distributions of the persons covered in the various sources.

⁸ Unfortunately it is not possible to condition the results on persons with AIDS who had a living parent because for a minority of cases (about 8 percent) the key informant did not know if there was a living parent. Since such cases always involved situations in which the person with AIDS did not live with or adjacent to a parent, leaving them out would lead to overestimates of the proportions of cases who coresided or lived adjacent to a parent.

⁹ To derive adjusted percentages for each 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, J., Frey, R., Chu, S., & 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, S., et al. (1994). The geography of AIDS: Patterns of urban and rural migration. *Southern Medical Journal*, 87(6), 599-606.
- Davis, K.A., Cameron, B., & Stapleton, J. T. (1992). The impact of HIV patient migration to rural areas. *AIDS Patient Care*, 6, 225-8.
- Ellis, M., & Muschkin, C. (1996). Migration of persons with AIDS- A search for support from elderly parents? *Social Science and Medicine*, 43(7), 1109-1118.
- Fuller, T., Lightfoot, P., & Kamnuansilpa, P. (1990). Urban ties and rural Thais. *International Migration Review*, 24, 534-562.
- Goldstein, S. & Goldstein, A. (1986). Migration in Thailand: A twenty-five-year review. Papers of the West-West Population Institute, No. 100.
- Knodel, J., & Saengtienchai, C. (1996). Family care for rural elderly in the midst of rapid social change: The case of Thailand. *Social Change*, 26(2), 98-115.
- Knodel, J., Saengtienchai, C., Im-em, W., & VanLandingham, M. (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, J., & Chayovan, N. (1997). Family support and living arrangements of Thai elderly. *Asia Pacific Population Journal*, 12(4), 51-68.
- Knodel, J., Chayovan, N., Graiurapong, S., & Suraratdecha, C. (2000). Ageing in Thailand: An overview of formal and informal support. In D. Phillips (Ed.) *Ageing in the Asia-Pacific regions: Issues and policies* (pp. 243-266). London: Routledge.
- Knodel, J., VanLandingham, M., Saengtienchai, C., & Im-em, W. (2001). Older people and AIDS: Quantitative evidence of the impact in Thailand. *Social Science and Medicine*, 52(9), 1313-1327.
- Muecke, M. (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.
- National Statistical Office, Thailand. (No date) *Report of the 1994 survey of elderly in Thailand*. National Statistical Office, Bangkok.
- Ntozi, J. P. M., & Nakayiwa, S. (1999). AIDS in Uganda: How has the household coped with the epidemic? In I. O. Orubuloye, J. C. Caldwell, & J. Ntozi, *The continuing HIV/AIDS epidemic in Africa: Response and coping strategies* (155-80). Canberra, Australia: Health Transition Centre, Australian National University.
- Richter, K., Guest, P., Boonchalaksi, W., Priyathamwong, N., & Ogena, N. (1997). *Migration and the rural family: Sources of support and strain in a mobile society*. Bangkok Thailand: Institute for Population and Social Research, Mahidol University, Report 190.
- Rumley, R. L., Shappley, N. C., Waiver, L. E., & Esinhart, J. D. (1991). AIDS in rural eastern North Carolina -- patient migration: A rural burden. *AIDS*, 5, 1373-8.
- Saengtienchai, C., & Knodel, J. (2001) *Parents providing care to adult sons and daughters with HIV/AIDS in Thailand*. UNAIDS Best Practice Collection, Geneva: UNAIDS, November 2001.
- VanLandingham, M., & Im-em, W. (2001). Living with HIV/AIDS: Results from a self-administered survey. *PSC Research Report* No. 01-488. Ann Arbor, MI: Population Research Center, University of Michigan
- Williams, A., & Tumwekwase, G. (Forthcoming). "We will be alone when we die": HIV/AIDS and the aged in rural Uganda. *Journal of Cross cultural Gerontology*.
- World Health Organization (WHO). (2001). Impact of AIDS on older people in Africa: Zimbabwe case study. Draft report: Sept. 2001.

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

Percentage distribution by	Nationally recorded AIDS cases 1997/1999	Cases reported the key informants	Deceased children from AIDS parents survey	PWA group member sample	Welfare applicant sample
Sex					
Male	75.3	73.9	79.8	33.3	53.0
Female	24.7	26.1	20.2	66.7	47.0
Total	100	100	100	100	100
Age					
20-24	10.8	11.4	9.6	10.0	13.6
25-29	29.5	30.1	33.2	30.9	29.7
30-34	26.9	24.7	33.4	27.9	29.9
35-39	15.8	17.1	15.5	15.9	15.5
40+	16.9	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	58.2	49.2	45.7	28.2	39.1
Divorced/ separated	4.3	9.1	12.9	13.2	8.5
Widowed	4.5	11.8	11.9	46.1	28.9
Total	100	100	100	100	100
N of cases (b)	--	960	394	408	826

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.

Table 2. Percentage of persons 20-49 who live with someone 50+ and percentages who live with a parent, unstandardized and standardized for age and sex: comparison of general population, PWA group members, AIDS welfare applicants and AIDS cases as reported by key informants

Measure and data source	% living with someone age 50 or over		% living with a parent	
	Unstandardized	Standardized for age and sex	Unstandardized	Standardized for age and sex
% living in same household or dwelling				
1990 Thai census	38.8	37.6	n.a.	n.a.
1994 general household survey	39.7	39.6	31.3	28.8
PWA group members	48.0	47.0	38.3	34.8
AIDS welfare applicants	55.4	59.5	56.0	60.0
Currently symptomatic persons as reported by key informants	n.a.	n.a.	51.9	50.4
Persons who died of AIDS as reported by key informants	n.a.	n.a.	61.7	61.5
% living in same household, dwelling or compound				
PWA group members	n.a.	n.a.	48.4	44.8
Currently symptomatic persons as reported by key informants	n.a.	n.a.	60.1	60.6
Persons who died of AIDS as reported by key informants	n.a.	n.a.	69.9	69.6

Note: Standardized results are calculated by using the age distribution of AIDS cases during 1997-99 as reported in Ministry of Health AIDS registry as the standard.

n.a. = not available

Table 3. Percent distribution of adult persons living with AIDS and those who died of AIDS according to their return migration status

Migration status	Persons alive with symptomatic AIDS in the community		Persons who died of AIDS in the community	
	All	Those living with or adjacent to a parent at the terminal stage	All	Those living with or adjacent to a parent at the terminal stage
Moved back to local area after becoming ill	25.9	31.4	36.7	40.8
Moved back to local area 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

Source: Key Informant Study

Note: Adult is defined as age 20 or over

Table 4. Percent of adult persons living with AIDS and those who died of AIDS who lived with parents during illness by return migration status

Living arrangement measure and migration status	Persons alive with symptomatic AIDS in the community		Persons who died of AIDS in the 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

Source: Key Informant Study

Note: Adult is defined as age 20 or over

Table 5. Percent moving back after onset of symptoms among adults who died of AIDS by sex and residence at time of death, unadjusted and adjusted by logistic regression

	Percent moving back		N of cases
	unadjusted	adjusted	
Total 20 and above	36.7	36.7	660
Sex		(p=.532)	
Male	36.3	36.0	504
Female	37.8	39.1	156
Residence at time of death		(p=.000)	
Rural	41.2	40.8	442
Urban	27.5	28.2	218

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 age, marital status and the other demographic characteristic 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.

Table 6. Residence and residential mobility among persons who died of AIDS as reported by AIDS parents

	All adult children	Sons	Daughters
% who lived with or adjacent to the respondent at the terminal stage of AIDS	89.1	88.1	92.8
N of cases	394	311	83
Of those who lived with or adjacent to the respondent at the terminal stage ^a :			
% who moved back during last two years	35.1	34.7	36.8
% who moved back after onset of symptoms	30.2	28.8	35.1
% who moved back because of illness	27.1	27.0	27.3
N of cases	350	274	76
Of those who moved back after onset of symptoms to live with or adjacent to the respondent, % who came ^a :			
Alone	45.3	43.0	51.9
with spouse	34.0	34.2	33.3
with children	21.7	17.7	33.3
with others	12.3	11.4	14.8
N of cases	106	79	27
Of those who moved back after onset of symptoms to live with or adjacent to the respondent:			
% who died less than a month after move	19.1	23.1	8.0
% who died less than 3 months after move	50.5	59.0	24.0
median length of residence before dying	2.5	2.0	6.0
N of cases	103	78	25
Of those who moved back to live with or adjacent to the respondent because of illness, % doing so for the following reasons ^a :			
need for care	68.8	65.7	80.0
spouse died or deserted	9.7	6.8	20.0
lost job/needed material support	35.5	31.5	50.0
needed psychological support	18.3	20.5	10.0
came home to die	16.1	19.2	5.0
N of cases	93	73	20

Source: Survey of AIDS parents

() = 10-19 cases

n.a. = not applicable

^a Percents add to more than 100 because for some respondents the categories are not mutually exclusive.