

John Knodel, Susan Watkins, and Mark VanLandingham

**AIDS and Older Persons: An International Perspective**

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## **AIDS and Older Persons: An International Perspective**

John Knodel, Professor  
Population Studies Center  
PO Box 1248  
Ann Arbor, MI 48106-1248  
USA  
FAX: 734-998-7415  
Email: [jknodel@umich.edu](mailto:jknodel@umich.edu)

Susan Watkins, Professor  
Population Studies Center  
3718 Locust Walk  
Philadelphia, PA 19104-6298  
Email: [swatkins@pop.upenn.edu](mailto:swatkins@pop.upenn.edu)

Mark VanLandingham, Associate Professor  
Tulane University  
School of Public Health and Tropical Medicine  
Dept of International Health and Development  
1440 Canal St., Suite 2200  
New Orleans, LA 70112-2737  
Office: 504 587-2113  
Email: [MarkVanLandingham@Tulane.edu](mailto:MarkVanLandingham@Tulane.edu)

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Address correspondence to John Knodel, Population Studies Center, PO Box 1248, Ann Arbor, MI 48106-1248, USA. Email: [jknodel@umich.edu](mailto:jknodel@umich.edu)

**Summary:** The impact of the worldwide AIDS epidemic on persons age 50 and over has received relatively little consideration except in the United States where interest has focused almost exclusively on older persons living with AIDS or at risk of infection. The place of older persons in the epidemic deserves international attention because their lives are being significantly affected in a variety of ways. Since most of the epidemic occurs in the developing regions, especially Africa and Asia, efforts to understand and deal with the concerns of older persons in relation to AIDS in those settings needs expansion. Although older persons represent a non-negligible minority of the reported global caseload, a far higher proportion are affected through the illness and death of their adult children and younger generation relatives who contract AIDS. From a global perspective, a broader concern encompassing those who are affected through the infections of others rather than a narrow concern with those who are at risk or infected themselves is called for if the needs of the large majority of older persons adversely impacted by the epidemic is to be addressed.

**Key words:** HIV/AIDS, Older persons, Parental caregiving, Thailand, Family

As most of the other articles in this issue attest, increasing awareness exists that older persons in the US are also at risk for HIV/AIDS and that their circumstances and needs may differ from those younger-aged on whom most research and intervention programs typically focus. Our purpose is to provide a global perspective on the overall impact of the AIDS epidemic on older persons with particular attention to the developing world, especially Asia and Africa. We argue that globally the greatest impact of AIDS on older persons occurs not to older persons who are HIV-infected but rather to those who are affected by others who are, particularly by their adult children and younger generation relatives who become ill and die of AIDS.

That the limited attention to how the HIV/AIDS pandemic impacts older persons has focused mainly on the United States rather than globally is unfortunate for several reasons. First, most older persons who are either infected themselves or who are affected through the infections of others overwhelmingly are outside the US, a country that accounts for less than 2.5 percent of the 36 million persons living with HIV/AIDS at the end of 2000 (1). In contrast, 70 percent of those infected are in sub-Saharan Africa and 16 percent in South and Southeast Asia (2). Second, the extent and nature of the impact on older persons likely differs in areas of the world where the epidemic is severest and the social, cultural, economic and political contexts very different. Finally, most research in the US focuses on older persons who are either themselves infected or at high risk of infection and ignores the broader range of consequences that are relevant for understanding how the epidemic affects older persons worldwide.

### **CONTRASTING EPIDEMIOLOGICAL AND SOCIAL SETTINGS**

Major differences among the AIDS epidemics around the world have implications for the impact on older persons. Prevalence levels are by far the highest in sub-Saharan Africa. Overall adult prevalence (for ages 15-49) for this region is estimated at 9 percent at the end of 2000 (2). In nine African countries more than 15 percent of adults are estimated to be infected and in Botswana the level exceeds a third (1). In the developing world outside Africa, levels are far more moderate with prevalence reaching 2 percent on a regional level only in the Caribbean. Still in Cambodia, Myanmar and Thailand in Asia and in five South American and Caribbean countries levels range from 2 to 5 percent. In contrast, adult prevalence in the US is about half a percent and in Western Europe only a quarter of a percent. Higher prevalence rates in Sub-Saharan Africa and parts of Southeast Asia ensure that greater proportions of older persons in these regions are likely to experience the loss of an adult child or younger generation relative than in countries where prevalence is low.

Contrasts in predominant modes of HIV transmission also are striking and bear on the impact of the epidemic on older persons. Men having sex with men (MSM) and injection drug use (IDU) are the predominate modes of HIV transmission in the U.S. and most other industrialized countries. Such behaviors are stigmatized by substantial population segments in the US and elsewhere where they predominate as modes of transmission. This value judgement could deter both gay men and drug users from turning to a parent for assistance when ill with AIDS, especially if the parent has not accepted the adult child's life style. In contrast, heterosexual transmission predominates throughout sub-Saharan Africa and in most higher prevalence countries in Asia and Latin America. Women primarily face risk through marital intercourse, a behavior that is universally morally acceptable. For men, the main risks are from patronage of forms of commercial or transactional sex, behavior that is generally acceptable in their societies. Thus, although AIDS itself is often stigmatized, there is likely to be less pressure in these contexts for HIV infected adults to hide the behaviors that led to infection from parents and thus one less barrier to turning to parents for help.

Particular combinations of culture, politics, and levels of social and economic development influence the consequences of the AIDS epidemic differentially between more and less economically advanced

countries and among countries within each broad grouping (3) (4). For example, the prevailing system of intergenerational exchanges of services and material support and the cultural prescriptions associated with it influence the likelihood an infected adult child will turn to parents for assistance. Living arrangements are a key factor influencing whether or not parents take on caregiving. In many developing countries, including those with substantial epidemics, informal familial systems of economic support and care for parents in older ages are common as is coresidence or living nearby adult children (5); (6). Considerable diversity exists in the extent and specific nature of these exchanges and arrangements between and within regions and even among different cultural groupings within countries. For example, in some societies older persons depend heavily on one child or mainly on sons; in others support is spread more widely over a broader kinship network. In general, old age support systems in Africa are based on a broader definition of family than in Asia. In Latin America formal support systems are more developed and some shift of dependence to these from informal familial support is thought to have occurred (7).

In addition to previously noted variations in the degree of social acceptability of the dominant behaviors associated with AIDS, the political context and the levels of social and economic development also influence how much the epidemic affects older persons. These factors help determine the availability of health insurance, health care facilities, and other alternatives to or assistance for home care. Far less public assistance to persons with AIDS usually is available in developing countries than in the US, thus necessitating greater reliance on informal care, often provided by older parents. Accessibility to effective treatment either for opportunistic infections or HIV itself also affects the need for, nature, and duration of parental caregiving. As parents can only be affected if they are still living when their adult child becomes infected or ill, overall adult mortality, as a determinant of parental survivorship, is important. Since caregiving tasks demand a certain level of physical and mental health, variations across settings in disability-free life expectancy also can play a role. Familiarity with HIV and AIDS also vary across settings. While older persons in the US generally know less about AIDS than do younger persons, much less is known about the situation elsewhere (8;9). For example, older persons in medium to high prevalence countries in the developing world may possess more first hand knowledge than their U.S. counterparts since they are more likely to have had personal contact with a person infected with HIV. Media attention given to AIDS varies across and within countries, another factor likely to influence knowledge and attitudes.

## **HIV/AIDS AMONG OLDER PEOPLE**

Considerable attention has been given to the fact that 11 percent of all reported cases of AIDS annually in the US are aged 50 and older. Yet little attention has focused on older persons with AIDS from a global perspective. Remarkably, the UNAIDS *Report on the Global HIV/AIDS Epidemic* and its subsequent update issued in June and December 2000 respectively refer only to children (age 0-14) or adolescents and young to middle age adults (age 15-49) as living with HIV/AIDS (1); (2). Since their estimate of the total global cases equals the sum of these two age groups, the algorithm gives the impression that no one age 50 or older becomes infected with HIV or is ill with AIDS. Indeed adult prevalence levels are conventionally cited in reference to the population age 15-49, a practice that further reinforces the image of older persons being spared by the epidemic.

Some system of AIDS case reporting exists in many countries, although quality and completeness vary enormously and AIDS cases typically are severely underreported. Nevertheless, such case reports are the only readily available source for empirically comparing the proportions of older people in the overall caseloads. As table 1 shows, statistics reported by national programs to WHO indicate persons aged 50 and over constitute a substantially lower share of reported AIDS cases in Africa, Asia and Latin America on average than in the US and other economically advanced countries with substantial numbers of AIDS cases. The proportions over age 50 is higher for men with AIDS than for women in all 3 developing

**Table 1. Older age persons as percent of AIDS cases**

| Region & Country | Total N | % of cases who are aged 50+ |      |       | 50-59 as % of all cases 50+ |
|------------------|---------|-----------------------------|------|-------|-----------------------------|
|                  |         | Total                       | Men  | Women |                             |
| Africa (1)       | 233336  | 5.6                         | 7.3  | 3.6   | 74.6                        |
| Asia (2)         | 119320  | 4.5                         | 4.8  | 2.9   | 67.9                        |
| Latin America(3) | 198322  | 7.4                         | 7.6  | 7.0   | 75.8                        |
| <u>Other</u>     |         |                             |      |       |                             |
| Australia        | 8096    | 9.3                         | 12.4 | 17.0  | 61.4                        |
| Canada           | 16235   | 11.2                        | 11.0 | 16.3  | N/A.                        |
| France           | 49421   | 12.9                        | 13.1 | 12.4  | 63.5                        |
| Germany          | 18515   | 16.4                        | 17.2 | 10.4  | 79.8                        |
| UK               | 16791   | 11.0                        | 11.7 | 5.6   | 75.6                        |
| USA              | 733371  | 10.7                        | 11.0 | 9.1   | 72.8                        |

*Source:* UNAIDS Epidemiological Fact Sheets for individual countries, 2000 Update; Centers for Disease Control and Prevention. 1999. HIV/AIDS Surveillance Report 11(2).

(1) Based on data for 26 countries; 65% of the cases attributable to Cote d'Ivoire and Tanzania;

(2) Based on data for 10 countries; 96% of the cases attributable to Thailand

(3) Based on data for 7 countries; 91% of the cases attributable to Brazil and Mexico

Note: Not all countries reported data by sex or in enough age detail to calculate cases age 50-59 separately from 50+ and thus results in these columns are based on few countries that for the percent 50+ for the total

regions although this gender difference is not consistent among the economically advanced countries. In all settings, however, most older persons with AIDS fall within the age group of 50-59.

In Africa and Asia where heterosexual intercourse is the predominant mode of transmission, higher rates for older men as compared to women likely reflect that sexual relations typically occur between couples in which the man is older than the woman. Most of the difference in the proportion of older people among reported AIDS cases in the developing world compared to industrialized countries is undoubtedly due to differences in population age structures. More developed countries (including the US) tend to be substantially older than less developed countries. Since older persons are a relatively larger share of the adult population in the more developed countries, they also constitute a greater share of AIDS cases. For example, in 1995, for every 100 persons 25-39 on average there were 48 persons aged 50-59 in more the developed regions but only 29 in the less developed regions (calculated from the United Nations assessment of the world population, the 2000 revision). Since most older aged AIDS cases are persons in their 50s, and most adult cases are aged 25-39, the older age structure of more developed countries would raise substantially the share of older AIDS cases among the total compared to less developed countries

Access to effective medical treatments, including anti-retroviral therapy, that have extended the lives of HIV positive persons to older ages is also far greater in developed than developing countries and likely also contribute to the higher share of older persons in the developed country caseload. Other factors such as nutritional and general health conditions may also lead to a longer average period between infection

and death in developed countries. Finally errors and differential completeness of reporting associated with age could bias the age distribution of cases.

## **CONSEQUENCES OF THE EPIDEMIC FOR OLDER PERSONS**

Although the number of older persons who will themselves be infected by HIV is not trivial, far more will experience impacts that derive from effects of the epidemic on the broader society and economy and through more immediate routes associated with the illness and death of an adult child or younger relative from AIDS. As members of the larger society and economy, older people are affected by the impact that an AIDS epidemic has at the macro-level (10); (11); (12). While discussing these macro level impacts is beyond the scope of this review, recognizing that such effects exist is important. Although the extent of such effects is under debate, it is likely to vary with the level of prevalence (13). If illness and death due to AIDS removes significant numbers of working age persons from the workforce, the old age dependency burden rises. In turn, this could hurt formal programs designed to assist or benefit older persons that depend on taxation and other forms of mandatory contributions from the current workforce. In addition, large numbers of persons with AIDS could compete for limited health services with older age persons who themselves generally have disproportionate health care needs. Moreover, to the extent that illness and death of workers due to AIDS lowers productivity and weakens the economy, the effects will spread to the general population including older age adults.

Unlike the indirect societal level effects, losing a younger family member to AIDS, particularly an adult son or daughter, can affect older persons through more direct pathways that profoundly alter their well-being. With the exception of attention focusing on older generations fostering AIDS orphans, such family level impacts largely have been ignored in the discourse about AIDS. In this section, we start with a general exposition of the potential pathways through which AIDS affects the well being of parents or other older family members. Next we review findings on these issues from Thailand where the most extensive research so far has been conducted on this topic. We end by reviewing the limited information available from Africa.

### **Pathways and Consequences of Family Level Impacts**

The AIDS epidemic affects older persons through multiple pathways that have potential consequences for their emotional, economic, physical, and social well-being. Parents of adults who become ill with and die from AIDS are likely the most common group of older persons who are seriously impacted. Thus we frame our discussion in reference to AIDS parents. However we note that other older generation relatives, such as grandparents or siblings of parents, could experience some of these same consequences.

Table 2 provides a general frame of reference for considering the main potential pathways through which the epidemic can affect AIDS parents, the relation of these pathways to different dimensions of well being, and the specific consequences that could result. This inventory is based in part on an earlier conceptual framework that guided our ongoing research in Thailand (14). How much these potential impacts actually occur remains largely for systematic empirical research to determine. They are likely to be context sensitive and thus to vary across different settings. Of the 7 pathways considered, the first five (caregiving, coresidence with the ill adult child, providing financial or material support during the time the adult child is ill, sponsoring the funeral of the deceased child, and fostering grandchildren) result in some sense from more or less volitional actions on the part of AIDS parents. Thus the parents have some degree of control over them. In contrast, parents have little or no control over the last two pathways (the loss of the child and negative community reaction) and thus less ability to manage the associated consequences for their well-being.



**Table 2. Potential pathways through which AIDS epidemic can adversely impact the well-being of parents of adult children with AIDS and their possible consequences.**

| Potential pathway  | Dimension of well-being and possible specific consequence<br>(see codes for possible specific consequence below) |                        |                    |        |
|--|--|------------------------|--------------------|--------|
|  | Emotional/<br>psychological  | Economic/<br>financial | Physical<br>health | Social |
| Caregiving   | A B C  | A                      | A B                | A B C  |
| Coresidence  | A C  | -                      | B                  | B      |
| Providing financial/<br>Material support during<br>illness | D  | B C                    | C                  | -      |
| Sponsoring the funeral                                     | C D  | B C                    | C                  | -      |
| Fostering grandchildren                                    | C D  | B C                    | C                  | A B C  |
| Loss of child  | D E  | D E                    | -                  | -      |
| Negative community reaction                                | C  | F                      | -                  | B D    |

Possible specific consequences  
(note PDA = person who dies of AIDS)

I. Emotional/psychological consequences

- A. psychological pain of seeing suffering and decline of PDA's health
- B. feeling overwhelmed by caregiving demands
- C. psychological pain from anticipated or enacted negative community reaction
- D. anxiety concerning consequences for economic security
- E. grief from loss of PDA

II. Economic/financial consequences

- A. opportunity costs of time taken from economic activities
- B. indebtedness from borrowing money to cover expenses
- C. depletion of savings or sale of assets to cover expenses
- D. disruption of PDA's contributions to parents' household
- E. loss of future support when parents are in old age
- F. loss of business from former customers out of fear of contagion

III. Physical health consequences

- A. physical efforts required by caregiving
- B. Risk of exposure to HIV (very low) or opportunistic diseases (esp. TB)
- C. Strain of additional economic activity needed to cover expenses

IV. Social consequences

- A. time taken away from social activities
- B. avoidance of social contact by others
- C. strained intra-familial relations
- D. strained social relations

*Caregiving.* Providing care to an ill adult child can affect all four dimensions of well-being of the older-age parent. As caregivers, parents can suffer considerable psychological pain witnessing the suffering and decline of their child. Caregiving demands enormous time and effort, especially at the terminal stage of AIDS. Parents may feel upset over anticipated or actual negative reactions from members of the community who associate the caregiving role with contamination by HIV. Adverse financial consequences could result when caregiving competes with time needed to earn a livelihood. Some caregiving tasks, such as lifting the ill adult child, may lead to physical strains. Also potential exposure to the opportunistic diseases (especially TB) exists if not to HIV (for which the risk of infection through caregiving is extremely low). Caregiving also can divert time from social activities or lead social shunning by others who have misgivings about being near the caregiver or the adult child with AIDS. Intra-familial relations become strained when caregivers perceive inequities in the contribution of other family members.

*Coresidence.* Some adult children who become ill with AIDS lived with their parents prior the onset of symptoms. Others return to the parental home because of illness. Not all coresident parents necessarily give care, although coresidence and caregiving are closely associated. Merely living with an adult child with AIDS has some of the same potential consequences as caregiving including the psychological pain of witnessing their child's decline and concern over anticipated or actual negative community reaction. Coresidence can also put a parent at risk of exposure to opportunistic infections and curtail normal social life if community members avoid contact.

*Providing material support.* Parents may help with medical and living expenses associated with the illness or with the upkeep of the ill child's dependents. To do this, parents may go into debt, deplete their savings, or sell assets to cover these extra expenses. Such contributions can lead to anxiety among parents over their own economic security. A parent may need to take on extra work to cover the costs, which, if physically taxing, could affect health.

*Funeral expenses.* Funerals often involve significant costs for surviving parents and affect their economic well-being in the same ways as the costs involved prior to the death. If community members avoid attending the funeral or act in offensive ways at the funeral (e.g. refuse food or avoid being near the corpse), parents suffer socially and emotionally.

*Fostering grandchildren.* AIDS Parents also may inherit responsibility for AIDS orphans with obvious financial implications. Emotional strains may result from negative community reaction towards the fostered grandchildren or worries about the costs of childcare. Physical strain and exhaustion can result from additional work required to cover these costs. Foster care may diminish social activities, lead community members to avoid the family for fear that the grandchild is infected, or strain intra-familial relations if conflicts over custody arise or foster parents judge other family members as negligent in shouldering adequate responsibility.

*Child loss.* An adult child's death can devastate parents and lead to lasting grief (15); (16). Anxiety can ensue when parents depend economically on the child or had planned to do so. Current economic well-being may decline if the child who died contributed financially to parental support or assisted in household economic activities. In addition, parents lose any potential support that the deceased child might have provided in their old age.

*Community reaction.* Negative reactions of others in the community towards the parents, either during the time of the child's illness or following the death, could cause psychological, economic and social distress. For example, a shopkeeper whose child dies of AIDS may lose business because customers fear contagion. If other family members have a similar fear, strained intra-familial relations may result.

## Thailand as a Case Study

Perhaps the most extensive information available on AIDS and older persons for a developing country comes from on-going research in Thailand specifically directed towards the topic. The project uses a combination of approaches that are described in detail in a series of articles and reports (17); (18); (19);(14) (20) (21) (22). Micro-simulation was used to estimate the number of older-age parents who eventually will be affected. Drawing mainly on community health workers in 85 rural and urban sites in 8 provinces and Bangkok, a key informant study provides quantitative data on living and caregiving arrangements for over 1000 cases of persons who were living with or died of AIDS and information on other circumstances for a subset of approximately 300 cases they knew best. Extensive quantitative data were also collected through direct survey interviews with approximately 400 AIDS parents (identified through key informants) and an equal-sized comparison group in three provinces. Extensive qualitative data were gathered through 20 in-depth interviews with AIDS parents. Generational differences in knowledge and attitudes towards AIDS was assessed through a survey of over 1100 older and younger adults. Additional data came from a self-administered survey of over 400 persons living with AIDS, open-ended interviews and focus groups with health service providers, and AIDS welfare applications. This multi-method approach permits identification of most impacts through which the epidemic affects older persons and allows cross-checking of results through triangulation from different sources.

*Demographic magnitude of impact.* Results from the microsimulations indicate that despite only 2 percent HIV prevalence, 13 percent of Thais over age 50 as of 1995 are likely lose at least one adult child to AIDS and 12 percent of these will lose multiple children. The chance of losing an adult child during one's lifetime will be 70 percent higher than if there were no AIDS epidemic.

*Caregiving and coresidence.* The data provided by key informants, reveals that by the terminal stage of illness two-thirds of adults who died of AIDS either coresided or lived next door to their parents. The percentage is even higher (79 percent) when considering only cases with a living parent are considered. A parent provided care for almost two-thirds of adults who died of AIDS and served as main caregivers for half. 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.

AIDS causes many adult children to return to live with the parents. According to the key informant study, a substantial proportion of adult children (40 percent) who were cared for by parents at the terminal stage returned home from elsewhere, often at an advanced stage of the illness. For example, according to the AIDS parents survey, about a fifth of those who returned for parental caregiving died within less than a month and just over half within 3 months.

While the characteristics of the parental caregivers vary, according to both the key informant study and the AIDS parents survey, the vast majority of AIDS parents were age 50 or older and about half were 60 or over when their child died. A strong gender dimension to caregiving exists with mothers more likely than fathers to provide at least some personal care and four to five times as likely become the main personal caregiver.

Health impacts on parents during caregiving can be substantial. The direct interview survey of AIDS parents found that among those who provided care for their ill adult child, more than half experienced fatigue, insomnia, and anxiety, two-fifths strained their muscles and a third had headaches or stomachaches. In-depth interviews with AIDS parents reveal that the experience is usually emotionally devastating and the grief long lasting.

In addition to caregiving tasks at home, health services providers report that parents often are involved in the interactions between the child with AIDS and health personnel as the result of accompanying the ill

adult child for medical appointments, staying with them during periods of hospitalization or seeking advice. The AIDS parents survey confirms this: 60 percent of AIDS parents said they had consulted with a health provider about their child and almost 70 percent report bringing the child to health facilities.

*Financial impacts.* Data from both key informants and direct interviews with AIDS parents indicate that in over half of the cases who had a living parent, a parent played a main role in paying for treatment. The AIDS parents survey also indicates that in half of the cases where a parent gave care to the ill child, one or both parents had to either stop or reduce their economic activities. In a third of these cases, this circumstance created serious economic difficulties for them. In 14 percent of all cases, a parent had to assume additional work to cover expenses associated with their child's illness or funeral. For about a third of all AIDS parents, the deceased child had been the main income earner for their household. While only 27 percent of all AIDS parents judged that the loss of their child's financial or other support worsened their economic situation substantially, more than half of those who were very poor reported affirmatively.

Basic government health insurance, which is widely available in Thailand, in many cases covers the costs of available treatment and helps to reduce its economic impact on families. According to the AIDS parents survey, 60 percent of the adult children who died of AIDS were covered by some form of health insurance, mostly through the government. In over half of these cases the insurance covered a substantial part of the medical expenses. Antiretroviral drug treatment, which has not been readily available in Thailand, was not covered and was largely unknown by those with AIDS and their parental caregivers. Availability and awareness, however, may increase rapidly in the future given the considerable pressure currently building both internationally and in country to increase accessibility to effective therapies and the publicity about this in the media. The duration of intensive parental caregiving is usually short (typically about a month, according to the parents survey) thus further moderating opportunity costs to parents resulting from interruption of economic activities.

*Community reaction.* Although some social stigma is associated with AIDS in Thailand, key informants and AIDS parents frequently reported positive reactions from others in the community (such as visiting, showing sympathy and bringing food) and not just negative reactions such as avoidance or gossip. Most negative reaction stems from fear of contagion, particularly from the person with AIDS rather than moral disapproval. Little residual negative community reaction appears directed at the families, including the parents, following the death of those who die.

*AIDS knowledge.* According to the survey of older and younger adults, AIDS-related knowledge is lower among older respondents. Older adults were about as likely as younger counterparts to have ever known a person with HIV or AIDS and 7.5 percent of the older sample ever lived with or cared for one. The results suggest that older persons are less likely than young adults to be reached by AIDS educational campaigns. They often cited friends and acquaintances as important sources of information. Seniors also are much more likely to overstate the risks of contracting HIV by casual contact such as through sharing a meal, eating utensils, or living quarters with a person with HIV or AIDS. Many also appear overly concerned about the risk caregiving would pose for HIV infection. Both in-depth and survey interviews with AIDS parents, however, indicate that when actually faced with dealing with an offspring having AIDS, only a minority express fear of becoming infected themselves.

In brief, evidence from Thailand presents a complex picture regarding the various hypothesized impacts of the epidemic on older persons as presented in Table 2. As AIDS parents, older persons become very involved with the living and caregiving arrangements of their infected adult children. The emotional toll of this experience is great. Although serious adverse impacts on material well being are not widely apparent, they felt most among society's poorest strata. Adverse impacts on physical health related to caregiving are apparent although the long term health effects remain unknown.

## Evidence from Africa

The scale of the AIDS epidemic is much greater in sub-Saharan Africa than anywhere else and thus the proportion of older persons affected is greater. Since differences in levels of economic development, demographic conditions, state capacity, culture, and their interactions all condition the effects of AIDS on older persons, however, the impacts in Africa are unlikely to be a simple multiple of those described for Thailand or that occur in other countries where HIV levels are far lower. Sub-Saharan Africa includes some of the world's poorest countries with limited state capacity to provide the required infrastructure to support significant intervention in the lives of their citizens (9); (23); (24). The heterogeneity that characterizes the region and the paucity of systematic research present formidable barriers to making confident generalizations about the epidemic's impact of AIDS on older persons in sub-Saharan Africa. Yet some commonalities exist within the region permitting cautious speculation and tentative comparisons with other settings. In what follows, attention is focused on eastern and southern Africa, regions where HIV levels are the highest.

Some features characteristic of much of sub-Saharan Africa are likely to exacerbate the impact of the epidemic, whereas others are likely to moderate it. The lack of a well developed public health service in many African countries means that the overwhelming burden for caring for persons with AIDS and for supporting orphans is virtually certain to fall on family members, including those in older ages. Given the lack of state support for the sick, traditional communal mechanisms for caring for those affected by the epidemic are likely to be well entrenched, somewhat cushioning the impact of the greater scale of the epidemic. In addition, grandparental care of children may be more routine than elsewhere because of relatively high levels of fertility, non-AIDS mortality and temporary migration of young adults to urban areas, longstanding and unrelated to AIDS, which often leaves children in the care of rural relatives, particularly grandparents.

*Demographic magnitude of impact.* Macro-simulations using estimates of HIV prevalence and other parameters for South Africa provide some information about the demographic magnitude of the impact of AIDS on the elderly (25). The results suggest that very substantial proportions of the children of older persons will die from AIDS. For example, more than a third of the daughters of older women will have succumbed to HIV/AIDS by 2010 before attaining ages 20-35. South Africa is among the hardest-hit countries, however and thus simulations using data from most other countries in eastern and southern Africa would likely show less demographic impact and thus less impact on the lives of older persons.

*Caregiving and coresidence* The plight of orphans and the grandparents caring for them is often featured in media presentations and the scholarly literature on AIDS in sub-Saharan Africa giving the impression this is the typical situation for children and elders (26). AIDS related mortality and morbidity are said to have "a devastating impact on family structure, income, household food security and the quality of care given to survivors long before the death of a productive family member or parent" (27). There is little systematic evidence, however, to support such claims.

Estimates of the magnitude of orphanhood based on assumed mortality and fertility rates are surprisingly modest. For example in Kenya, with adult infection levels of about 14%, an estimated 4.1% of children under 15 in 2000 were maternal or double orphans; of these, 69% were due to AIDS. For Botswana, where an estimated third of adults are infected, 7.2% of children under 15 are maternal or double orphans, of whom 55.3% are attributable to AIDS. Corresponding figures for sub-Saharan Africa are 5.9% of children under 15, of whom 47.2% were AIDS orphans (28).

Although care of orphaned children often is assumed to fall to their grandparents, the few systematic examinations that exist show that not only grandparents but also surviving parents, and other relatives all serve as important caregivers to these children, with little difference between AIDS orphans and those

from other causes (29); (30). In a study in Uganda, the proportion of “skipped generation” households (grandparent, grandchild with the middle generation missing (but perhaps with other relatives) was under 1% in 1992 and 1.6% in 1995 (Ntozi and Zirimenya 1999: 199). Interestingly, caretakers of orphans now sometimes come from the maternal rather than the paternal line, even where traditionally the paternal line was expected to shoulder the responsibility, suggesting cultural change in response to AIDS (31). Quite different from the Thai case is the apparently fairly frequent occurrence of multiple orphans being cared for by the same caregiver - an average of 3 orphans per guardian in one such study (30).

Besides caring for orphans, older people in households in sub-Saharan Africa help care of those who are ill. Qualitative research in Uganda and Ethiopia and anecdotal and some survey evidence in Zimbabwe stress the important role of parents in caring for AIDS-afflicted adult children (24) (32);(33;34). One rare study providing quantitative estimates of caregiving was conducted in 1995 in six districts in Uganda (29). A parent was the primary caregiver for 48 percent of the almost 400 persons ill with AIDS or AIDS related diseases during the prior month, a figure similar to the Thai finding that parents were main caregivers for 50 percent of cases among the AIDS deaths studied (17). The inadequacy of the health systems and the poverty of families ensures that much of the care of persons with AIDS is home-based. Such care is likely limited to providing food, feeding patients who are unable to feed themselves, bathing the patient, doing laundry, and simply being present (34). This is certain to continue during the AIDS epidemic: indeed, there is some evidence that when hospital personnel know or believe that the patient has AIDS, they are likely to be dismissed to the care of relatives (27). Some studies in Tanzania have reported a trend towards shorter hospital stays for AIDS patients with the likely effect that more terminally ill are cared for at home (35). Intensive care is likely to be limited to short periods of illness when opportunistic infections can be cured and to a relatively short period before death. In eastern and southern Africa, the division of household labor is such that men have primary responsibility for earning money, including money for medicine, whereas women have primary responsibility for household chores, including care for the sick (36); (37); (38). Because these gender roles are firmly entrenched, they likely will persist during the AIDS epidemic.

It is reasonable to expect that the illness and death of a patient takes a toll on the caregivers. The WHO study of older caregivers in Zimbabwe found that 39% stated they had experienced physical illness after the death of a PWA under their care and almost equal number said they experienced emotional stress. However, a longitudinal study in Northwestern Tanzania of the impact in a household of an adult death (most of which were due to AIDS) on elderly members (regardless of caregiving status) provide partial confirmation of the potential impact. The results show elderly in both poor and non-poor households experienced a significant drop in a body-mass index (BMI) following an adult death but BMI recovered over time and no long-run association with BMI levels and recent adult deaths is apparent (39). Interpretation of these results is hampered because changes in BMI presumably pick up only the most traumatic effects upon the health of elders.

*Financial impacts:* The financial impact of AIDS illnesses and deaths, especially on older persons, are difficult to determine from the available studies. In a survey of households in northern Uganda, 65 percent of respondents whose household lost an adult age 20-39 to an AIDS related cause said the most important consequence was “financial ruin”. This characterization is slightly higher than for cases where the death was due to other causes (Ayiga et al. 1999:table 9). Other studies offer insight into the details of the financial impact. A study in Tanzania found that the sum of the medical and funeral costs associated with AIDS exceeded the estimated annual household income per capita, with direct medical costs about 1.5 times higher than the funeral costs; during their terminal illness those with HIV/AIDS made more extensive use of both traditional and modern health services than people who died from other causes, primarily because of the longer duration of illness (35). Neither study however distinguishes households with elderly members from others.

The loss of remittances from adult children working in cities or the loss of household labor of adult children in rural areas can be expected to affect the standard of living of the elderly (34). However, the extent and magnitude of these remittances from urban-based children appear rather small. A study in Zimbabwe found that only 48% of the elderly received any remittances from their children. Of those who did receive something, 70% received less during a year than the cost of a single month's supply of food (40). Analysis of the data from the study in rural Kagera, Tanzania found no impact of illness or death of prime-aged adults on time others in the household spent working on the farm (41). This may be because there is little shortage of labor in this area or because households rapidly adjust to a prime-age death by bringing in new household members (42).

*Community reaction:* Early in the AIDS epidemic in eastern and southern Africa considerable stigma was associated with HIV/AIDS which could affect older families members associated with the person with AIDS . Overall, we expect stigma to decrease as AIDS deaths become more common. In Uganda, for example, over half the respondents in a survey conducted in 1995 in Masaka knew more than 10 people who had died of AIDS and reported an average of 3.2 family members (defined as "from your grandmother's house") dying of AIDS (32) (Table 4, p.161). In one study in Zimbabwe, where more than half the respondents reported having relatives with AIDS, stigma appears to have waned (43); (44). In another survey in Zimbabwe , only 27% of older persons from households associated with AIDS reported experiencing stigma. (34)

Clearly there is need for much more careful research documenting the impacts of the epidemic on older persons in Africa. The limited evidence so far suggests that, as in Thailand, parents are very much involved in providing care for their infected adult children. Because fertility levels are relatively high in Africa, however, parents are more likely to experience the illness and death from AIDS of several children. Serious adverse impacts on material well being are not yet widely apparent, but they are likely to be greater than those measured in Thailand because the families of the infected are generally poorer and have less access to public assistance.

### **Comparison to US Situation**

The higher prevalence rates for AIDS and larger family sizes of older parents in developing countries with moderate to severe epidemics increase chances of older persons losing a child when compared to the situation in the US. Moreover, the high level of parental involvement with adult children ill with AIDS that has been systematically documented in Thailand and Uganda and supported by anecdotal evidence elsewhere contrast sharply with the US (and probably other western countries). According to a 1990 national study, only 13% of AIDS caregivers were 50 or older and only 6% at least 60 (45). The role of parents in this US study cannot be directly assessed since the relationship of caregivers to the person with AIDS was not asked. The authors infer that substantial numbers of caregivers were gay men. Another study of a sample of persons with AIDS from San Francisco and Los Angeles found that less than 10% of caregivers were mothers and very few were fathers (46). Almost three fourths of caregivers had non-family relationships to the person with AIDS, most being partners, lovers or friends. One study of persons living with AIDS in New Jersey, the majority of whom were injection drug users, reported 40 percent were living with "parents or other family of origin" and 31 percent of respondents reported their mother as the single primary helper (47). A very high non-response rate in this study, however, limits interpretation and may explain some of the apparent discrepancy with results from the national sample results discussed above.

While parental caregiving to adult children with AIDS undoubtedly is less common in the US than in most developing countries, the focus of most US studies on persons currently ill with AIDS, rather than persons who have already died, probably leads to underestimates of its extent. As documented in Thailand, and for which there is indirect evidence for the US, some adults who live away from their

parental home at the onset of symptoms return for assistance at more advanced stages of illness (48). Thus cross-sectional studies of current caregiving to persons living with AIDS under-represent how much parents eventually become involved.

Several reasons explain why parental caregiving and material support might be considerably less common in the US than in many developing countries. In most developing countries, institutional forms of care and financial support for persons with AIDS are quite limited when compared to the US. Thus persons with AIDS in developing countries depend more heavily on informal channels of care and support. In addition, support from adult children to older aged parents, including coresidence with them, are common in much of the developing world. Thus a sizeable minority of adult children already live with or nearby a parent before becoming ill in countries with serious epidemics. Older parents not only receive help from adult children but also provide important services for them. Turning to parents for long term residential care by an adult child is thus quite congruent within this familial support system. Also, heterosexual transmission, which predominates in many developing countries, is relatively unstigmatized, even when it involves transactional sex. Thus it might not be a barrier to seek assistance from a parent in the same way that a gay lifestyle or injecting drug use, the predominant risk behaviors in the US, could be.

## **CONCLUSIONS AND RECOMMENDATIONS**

Globally a sizeable number of middle and older aged persons are infected or at substantial risk of HIV infection. A far larger number have been impacted in consequential and adverse ways through the infection of their adult children and younger generation relatives. Yet little attention has been given to persons age 50 and over in either sense, particularly outside the US. To conclude this review, we first speculate on how these circumstances may change in the foreseeable future. We end with recommendations for research on older persons and AIDS.

### **Potential Future Trends Affecting Older Persons**

The effects of the AIDS on older persons could change dramatically as the epidemic's consequences are absorbed by the societies where it occurs and as social and medical responses to the epidemic evolve. If existing systems of old age support breakdown or are altered because of widespread infection and incapacitation of working age adults, older persons will be forced to either forego the income expected from younger relatives and adjust their standard of living downwards or replace the lost income from other sources. Widespread orphanhood also bodes poorly for older persons in medium to high prevalence developing countries, since grandparents often become surrogate guardians when parents are unavailable to raise their young children.

More hopeful are expectations of increasing availability of anti-retroviral therapy and more effective treatments of opportunistic infections. Availability would lengthen the productive life spans of HIV infected young adults who have both older persons and young children dependent upon them. Such progress also could expand the role (and the burden) of older persons as liaisons between their ill adult children and the health care system. Lengthening the lives of adults with AIDS would also increase the share who survive into their fifties and beyond, thus augmenting the proportion of the caseload that are older persons. Given the increase with age of a variety of chronic conditions and general susceptibility to other infections, this could in turn lead to interactions between AIDS and other health problems normally associated with older age morbidity.



## **Suggested Research Agenda And Priorities**

Research is needed on a variety of fronts if we are to understand the risks and problems related to older persons who are HIV infected and also the impacts experienced through the infection of others, particularly their adult children. Without a better research foundation, developing appropriate programs and policies to address the special needs of older persons or to utilize their potential as human resources in combating the epidemic and its overall consequences will be all the more difficult. Here we suggest some potentially important areas for future research.

*Consequences of the epidemic for older persons as parents and relatives of HIV infected adults.* As discussed above, the main impact of the epidemic on older persons in most countries is through the social, emotional, economic and health consequences of being a parent or relative of a younger person who dies of AIDS. Yet little attention is given to these outcomes other than with respect to inheriting AIDS orphans. Explication of the full range of impacts and how they differ across a variety of settings should be of the highest priority for international research. These same issues, particularly parental caregiving, are under-investigated with regards to the US and merit research as well. The studies should be conducted with an eye to developing interventions to mitigate the adverse effects, to assist older persons in their caregiving roles, and to harness their potential as intermediaries between the health care systems and those with AIDS.

*Impact of AIDS mortality and morbidity on social security, pension, health and welfare systems.* That most HIV/AIDS occurs among adults in the prime economically active years has implications for public financing of services for the older population including health care, social security and pension schemes, and welfare measures. Impacts likely operate through reducing contributors to the funding and by creating competition for funds or services that otherwise would be directed to the older population. The impacts will depend on the nature, coverage and even existence of such programs. Assessing the current extent of impacts and projecting their likely future course is necessary if the adverse effects for the older population are to be minimized.

*Sexual behavior and practices of older persons.* In the majority of countries with moderate to severe epidemics, the predominant mode of transmission is heterosexual relations. Yet almost no systematic research has been done on the sexual activity and practices of older adults in these countries. Attention should be directed to both marital and extramarital sexual behavior, especially the involvement of older men in transactional or commercial sex patronage.

*Estimating the demographic extent of impacts on older persons.* Few developing countries have reliable age profiles of either the HIV infected population or of AIDS cases. Determination of how many older persons are infected in different regions is needed. Both internationally and for the US, HIV/AIDS data need to be provided in more refined age categories than those currently available. The value of differentiating the “young old” from the “older old” has long been recognized in studies of morbidity, mortality, and the changing needs of people as they age. Larger samples may be required if studies in both the US and elsewhere are to adequately document the demography of the epidemic among older persons. Also assessing the demographic magnitude of various impacts on older-aged persons that arise from the illness and death of a adult child or relative is important.

*Methodologies to study the family level impact on older persons.* Research into how the illness and death of an adult child or younger generation relative affects the lives of older family members, especially parents, presents considerable methodological challenges. Approaches need to be developed for overcoming difficulties arising from problems in identifying the population of appropriate cases and controls, drawing a reasonably unbiased and sufficiently large sample for quantitative analysis once identified, and the sensitive nature of subject matter.

*Interactions between the health care system and older-aged caregivers.* Although older persons play a crucial role in AIDS caregiving, arranging for treatment, and accompanying persons with AIDS to health facilities for service, little is known about the extent and manner of their interactions with the formal health care system. Research is needed to assess, for example, if they receive appropriate caregiving advice or their own health needs as caregivers are addressed. Such research also might assess the need for home visits to assist older caregivers.

*The potential of older persons as intermediaries in HIV prevention and treatment programs.* As parents and relatives, older persons have a substantial stake in encouraging safe behavior among younger adults. They may also have the emotional and material leverage to do so. Developing interventions that take advantage of these assets could significantly contribute to stemming the epidemic. Older persons, particularly in their parental caregiving role, also possess untapped potential to serve as intermediaries between formal health services and infected adults. Research is needed to assess how to harness this potential to facilitate expanded prophylaxis and treatment of opportunistic infections and/or treatment of HIV through antiretroviral therapy. Investigation into how older caregivers might provide peer counseling and socio-emotional support to other older persons in the same predicament also would be useful.

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