

Mark VanLandingham, John Knodel, Wassana Im-em, and  
Chanpen Saengtienchai

**The Impacts of HIV/AIDS on Older Populations in  
Developing Countries: Some Observations based upon  
the Thai Case  
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Population Studies Center, University of Michigan  
PO Box 1248, Ann Arbor, MI 48106-1248 USA

**The Impacts of HIV/AIDS on Older Populations in Developing Countries:  
Some Observations based upon the Thai Case**

Mark VanLandingham, Tulane University  
John Knodel, University of Michigan  
Wassana Im-em, Mahidol University, Thailand  
Chanpen Saengtienchai, University of Michigan

Corresponding author:

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  
Mark.VanLandingham@tulane.edu  
Fax: 504 584-3653  
Phone: 504 587-2113

Mark VanLandingham studies social aspects of health and illness in both U.S. and developing country populations. His current research focuses on the AIDS epidemic in Thailand and health adaptations among Vietnamese immigrants.

John Knodel has been conducting qualitative and quantitative research on a wide variety of social demographic topics in Thailand since 1971. His current work focuses on aging.

Wassana Im-em studies social and demographic aspects of reproductive health. She is currently engaged in a project focusing on domestic violence against women in Thailand.

Chanpen Saengtienchai has been conducting research on aging issues and sexual behavior in Thailand for the past 10 years. She uses surveys and qualitative techniques in her work.

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## ABSTRACT

We describe features of the older population and the history of the HIV/AIDS epidemic in Thailand, and discuss potential links between them. We address both direct and indirect impacts of AIDS upon the Thai older population, but focus our discussion on how older persons could be indirectly affected by AIDS infections occurring among their adult children. We identify five major mechanisms through which these indirect effects can occur: via finances, health, time commitments, social relationships, and emotional status. We discuss factors that could affect the degree and the distribution of such impacts. We then propose a research agenda for exploring the impact of AIDS upon older persons in developing countries, drawing upon our current research project on this topic in Thailand. We suggest a number of substantive areas that warrant investigation, and discuss the advantages and weaknesses of a number of methodologies that could be used to pursue these topics.

## INTRODUCTION

Many countries in the developing world are confronting two issues that were largely unanticipated until quite recently: the aging of the population and the onset of the AIDS epidemic. Each of these phenomena has resulted in new social challenges, demands for resources, and research agendas, but few social scientists have examined the interrelationships between AIDS and the welfare of older populations.<sup>1</sup> This is because until now the impact of AIDS upon older populations has not been readily apparent. AIDS strikes hardest and most directly at young adults, and although older persons are perhaps infected themselves more often than previously thought (Gross 1997), current epidemiological data indicate that the impact of AIDS on older persons would be largely indirect, that is, these impacts most often result from the infection of significant others.

This paper focuses on the various mechanisms by which older persons living in developing countries can be indirectly impacted by the AIDS epidemic. We do this by drawing upon our current research examining this issue in Thailand. We begin by reviewing the general situation of older persons in Thailand, focusing on population size, living arrangements, and sources of support. We then describe the Thai AIDS epidemic, including estimates of the number of persons infected, age and sex distributions, trends in these numbers and distributions, and projections of the future burden of AIDS cases. Next we outline the potential mechanisms by which older persons can be impacted by the AIDS epidemic, and discuss the possible influences of several mediating factors. We close by proposing a set of research questions that warrant attention both in Thailand and in other developing countries experiencing AIDS epidemics; and discuss the advantages and weaknesses of a number of methodologies that could be used to pursue these research questions.

## BACKGROUND

### *The Thai Older Population*

Thailand, like many other middle income countries, is experiencing a significant increase in both the numbers and percentages of older persons in its population. The increase in absolute numbers is due to prevailing high levels of fertility when today's older persons were born, combined with lengthening life expectancy. At mid century the total

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<sup>1</sup> Older populations are defined in various ways. For this study we generally focus on populations aged 50+ and 60+, since these bounds will include individuals who are old enough to be facing retirement and in many cases financial dependency in the near future. This definition also provides for a population young enough to include many who will face a significant risk of experiencing an adult child death before the end of their own lives. For a review of the potential impacts of AIDS on non-infected family members, see Palloni and Lee (1992).

fertility rate is estimated to have been over 6 births per woman and it is likely to have been at this level for much of the past (United Nations 1998). In sharp contrast, total fertility is currently under two births per woman and is expected to remain low for the foreseeable future (Knodel et al. 1996b, Hirschman et al. 1994).

The increasing *percentage* of older persons in the population is due mostly to the remarkable fertility decline that occurred in Thailand (and in numerous other developing countries) during the 1970s and 1980s.<sup>2</sup> During and since this era of fertility decline, reproductive age couples were having substantially fewer children than previous generations had. Meanwhile, successive cohorts of older persons, who were already born during the previous era of high birth rates and were aging under a regime of declining mortality rates, continue to increase in number. Thus the proportion of the population comprised of older persons continues to grow.

Knodel and colleagues (in press) have documented some of these trends. They find a steadily increasing number of persons age 60+ in the population, rising from 1.7 million in 1970 to a projected 14.9 million in 2030. More critically, the *percentage* of older persons in the population rises from 4.8% to 21.1% . As older persons increase as a percentage of the overall population, this results in an increasing ratio of the number of older persons per working age adult who is potentially available to support them (the old age dependency ratio). This ratio increases from 0.10 in 1970 to 0.35 by 2030.

This increase in the numbers and percentages of older persons and in the old age dependency ratio occurs at a time when a comprehensive social security system is only beginning to be established. But these trends also occur within a social context of longstanding and strong norms regarding filial obligations to parents. (For a discussion of filial piety in the Korean context, see the article by Levande, Herrick, and Sung in the July 2000, issue of this journal). Expectations of old age support to parents in the form of either remittances and/or coresidence are widespread (Pramualratana 1990; Knodel, Saengtienchai, and Sittitrai 1995), and survey data indicate that these expectations are borne out in practice (Knodel et al. in press). Although the percentage of older parents coresiding with at least one child has declined modestly in the last decade, by 1995 nearly three-quarters of older persons with children still do so. Ninety percent of older persons with a child either live with one or have daily contact with one.

Norms supporting remittances from children to support their older parents also correspond well with actual behavior. Eighty-nine percent of older persons having a child living outside the household received food or clothes from them

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<sup>2</sup> For a discussion of the Thai fertility decline, see Knodel et al. (1987).

during the past year. Eighty-eight percent receive monetary support, and 69% receive significant amounts of monetary support (over B1000 or approximately \$27). Almost half (49%) of older persons 60+ report that their *main* source of support is their children (Knodel et al., in press).

### *The Thai HIV/AIDS Epidemic*

Thailand currently faces a moderately severe AIDS epidemic. Prevalence levels are much higher than those found in the United States and western Europe, but much lower than those found in the hardest hit African countries such as Malawi and Uganda.<sup>3</sup> Careful and extensive surveillance of cases since the onset has resulted in the Thai AIDS epidemic being one of the best documented in the world. The spread of the virus that causes AIDS through various population subgroups has been monitored by the Thai Ministry of Public Health and other groups through HIV antibody testing among high risk groups. Sex workers, intravenous drug users, and soldiers have been accessible for testing and monitoring since many members of these risk groups are already in contact with various government bureaucracies. Now that HIV has spread throughout the population, antibody testing provides a less comprehensive picture of the overall situation since infected persons are now much more varied and more difficult to locate and monitor. Estimation of current levels of infection based upon reported AIDS cases is unsatisfactory, since many AIDS deaths are not reported as such in Thailand. Also, estimates of age/sex distributions that are based upon official statistics must be interpreted with caution since there may be differential underreporting by these categories.

These shortcomings of official data aside, it is well established from sentinel surveillance data that the earliest Thai AIDS cases occurred during the middle to late 1980s among men who have sex with men and among intravenous drug users. But by the early 1990s the virus had established itself firmly within the population of sex workers and the men who patronize them (Brown et al. 1994). Both the providers and purchasers of sex services are concentrated in the late adolescent and young adult ages. Reported AIDS cases are heavily concentrated in the age range 20-39, accounting for almost four-fifths of all cases through 1998 (Thailand Ministry of Public Health web site 1999). Only 4 percent of reported cases are aged 50 or older.

While there is little doubt that the bulk of infections and deaths occur among young adults primarily in their 20's and 30's, it is quite possible that the reported numbers of AIDS cases among older Thais underestimate their share of total

victims. For example, health officials are probably less likely to consider older persons to be at risk of this disease and thus may not diagnose AIDS as readily for an older person as for a younger adult. If true, then some proportion of AIDS-related deaths among older persons would be misclassified as deaths due to other causes. In addition, if therapies that prolong the life of HIV infected persons become more widely used in Thailand, the numbers of persons infected at younger ages but who survive to past 50 will increase.

Information on sexual practices and patterns that would put one at risk of HIV infection is unavailable for the Thai older population (and rare elsewhere), but recent data do indicate that a substantial number of Thai older persons remain sexually active. Chayovan and Knodel (1997) in an analysis of the nationally representative 1995 Survey of Welfare of Elderly in Thailand find that among those age 50-59, 53% (62% for married men; 46% for married women) report having sex in the past month. Among those age 60-69, 22% report sexual behavior in the past month (28% for married men; 17% for married women). Data on number and types of partners are not available. More information about the sexual lives of older persons is needed both for Thailand and for other developing countries in which HIV is widespread.

In addition to these variations by age, AIDS and HIV infection rates also vary by sex. The fact that (until very recently) a large number of Thai men engaged in commercial sex with a relatively small pool of female sex workers<sup>4</sup> is reflected in the substantially greater number of reported AIDS cases among males than among females, since current cases roughly reflect incidence levels approximately 5-10 years ago. Cumulatively through 1998, there are 3.8 male cases for every female case (Thailand Ministry of Public Health web site 1999). Government data on *recently* reported AIDS cases indicate that this sex differential is diminishing. AIDS is now spreading to the population of married Thai women, many of whom have been infected through their husbands (Brown et al. 1994). This spread to the general married female population is reflected by a decline in the sex ratio (male/female) of reported AIDS cases from 4.6 for cumulative cases through 1996 to 2.9 for 1998 cases (Thailand Ministry of Public Health web site 1999). This ratio is expected to continue to decline as more women become infected over the next decade (NESDB 1994).

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<sup>3</sup> Hereafter we refer to the HIV/AIDS epidemic as the AIDS epidemic. For current infection rates for Thailand and other countries, contact the website for UNAIDS: [www.unaids.org](http://www.unaids.org).

<sup>4</sup> The most careful estimates put the number of sex workers at between 75,000 and 150,000 in 1994 (Boonchalaksi and Guest 1994). It is almost certainly less than that now (Hananberg and Rojanapithayakorn 1998).

Infection rates vary widely by region, and are highest in the northern part of the country. HIV prevalence rates among pregnant women range from over 10% in some northern provinces to less than 1% in some central, northeastern, and southern provinces.<sup>5</sup> Military recruit data also indicate much higher levels among soldiers in the north (Mason et al. 1995).

Cumulatively, by 1997 approximately 1 million cases of HIV infection or AIDS had occurred within a Thai population of about 59 million (United Nations AIDS Division (UNAIDS) 1998a). While exact numbers and projection trends are subject to contention,<sup>6</sup> it is generally agreed that incidence has peaked and will continue to decline for the foreseeable future. This is due in part to the success of Thailand's efforts to slow the spread of HIV by encouraging brothel owners to implement a 100% condom policy with clients (Chamrathirong et al. 1998), and by aggressive treatment of other sexually transmitted diseases that facilitate the spread of HIV (Hananberg et al. 1994). Increasing fears among young men about the dangers of commercial sex patronage has also undoubtedly played a major role (Knodel et al. 1996a, UNAIDS 1998b).

It is also generally agreed that the bulk of the care taking burden for PWAs will occur during the next 10 - 20 years as, barring a medical breakthrough, those individuals recently infected but currently asymptomatic begin to become ill and require care. The medium level projections from the NESDB (1994) imply that the numbers of AIDS deaths will peak between the years 2000 and 2005, and slowly decline thereafter (Figure 1). The implications of these trends for the Thai older population are discussed in the next section.

#### POTENTIAL PATHWAYS OF AIDS IMPACTS ON OLDER POPULATIONS

Although the number of older persons who will suffer from AIDS themselves is not trivial, a far greater number of older persons will be affected by the epidemic indirectly through their relationships to younger adults who are AIDS victims. In the remainder of this article, we focus upon those older persons who are affected by the AIDS epidemic through the infection of others. AIDS epidemics can affect non-infected older persons through their impacts on larger

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<sup>5</sup> The median infection level among antenatal clinics for women attending these clinics was 2% in 1997 (UNAIDS 1998a).

<sup>6</sup> The results of estimation procedures are very sensitive to even minor differences in the input values, e.g., the anticipated rate of decline in incidence.

economic and social forces and/or by affecting in more immediate ways families who have a PWA (person with AIDS). These potential impacts are diagrammed in Figure 2.

### *Macro-level impacts*

Older populations in developing countries experiencing moderate to severe epidemics are likely to face a number of effects at the macro level (see top half of Figure 2). The magnitude of these effects will depend upon a number of factors, the first being the overall level of HIV infection among working age adults. This overall level of infection is in turn determined by both behavioral and biological factors. The extent of risk taking behavior (e.g., unprotected sex between sex workers and their clients) among young adults is affected by long standing social norms governing their practice, as well as more recent social responses to the epidemic. In Thailand, social response includes behavioral change due to an increasing recognition of the risks involved and to various interventions (e.g., requiring condom use at commercial sex establishments) implemented by the government and other organizations. Successful biological interventions can also affect the overall infection level. Widespread treatment of STDs (an important cofactor of HIV acquisition) and possible future vaccines can lower the overall number of infected young adults in these countries.

Widespread infection of young adults leads in turn to a number of macro-level effects on the older population. First, as working age PWA adults are removed from the work force when they become ill, the old age dependency burden will become higher for those remaining in the work force, i.e., there will be more older persons per working individual. While many working age persons who contract AIDS may not in fact have been sending remittances to support an older parent, a higher old age dependency ratio means that individuals who *potentially* could have helped support an older person are no longer available to do so.

The removal of working age individuals from the work force will be especially disruptive for economies such as Thailand's that have recently experienced a severe economic downturn. Cohen (no date) anticipates that the main economic effects of an AIDS epidemic will be on savings and labor supply. In Thailand, the loss of productive workers early in their careers may exacerbate an already disrupted economic situation, making transfers from the working population to the dependent older population even more problematic. Also, some PWAs will be drawing upon already strained government and other social resources set aside to care for the sick. Given older persons' disproportionate need

for health services relative to the needs of other age groups, older persons are particularly likely to be affected by this competition for limited health care resources (Knodel, Chayovan and Siriboon 1992).<sup>7</sup>

The connection between these infected young adults and the macro level impacts described above will be moderated by any changes in mortality and morbidity among young adult PWAs and mortality levels among older persons. Any future treatments that lead to improving health and longevity among PWAs will weaken the link between the infection of young adults and the macro level impacts. Any changes in the survival probabilities of older persons will also affect the link between infected young adults and effects on the older population (e.g., decreasing mortality among the old by itself would put more older persons at risk of experiencing the death of a child due to AIDS). Resources available to the older population to assist them with these unfortunate circumstances will moderate the connection between the macro level effects and the well being of the older population. Such resources could include older persons' own personal and financial assets; family resources; and government or NGO programs targeted for this population.

#### *Micro-level impacts*

The principal ways in which older persons can be affected by the AIDS epidemic at the individual and family levels are outlined in the bottom half of Figure 2. The first two boxes address the question of which older persons are most likely to experience the infection of an adult child with HIV. Again, these influences can be divided into behavioral and biological components.

Behavior that puts one at risk of HIV acquisition is not random but rather is closely associated with key social and demographic characteristics. Region of residence is a key factor in any assessment of the distribution of AIDS' impact in Thailand. Levels of infection are much higher in the upper north than in other regions, and within the upper north, some communities are much harder hit than others. That these regional differentials are due to more lenient norms regarding the purchase of commercial sex in the north is suggested by localized studies (e.g., Lyttleton 1999) but difficult to verify in the absence of up to date and nationally representative data on sexual behavior. A representative sample of sex workers would be very difficult to obtain even in Thailand, but a disproportionate number are believed to come from the north (Boonchalaksi and Guest 1994).

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<sup>7</sup> For further reading on more general macroeconomic impacts of AIDS on Thai society, see Viravaidya, Obremskey, and Myers (1993); Bloom and Glied (1993); and Giraud (1993).

Socioeconomic factors will place some adolescents and young adults at higher risk of engaging in behaviors associated with HIV and AIDS than others. While the distribution of AIDS infections by social class remains understudied, research conducted during the early years of the epidemic indicate that the distribution of sexual behaviors that perpetuate AIDS varies by social group, with the less privileged being more likely to engage in behaviors that most likely lead to HIV and AIDS (VanLandingham et al. 1995). The probability of selling sex is likely higher among the poor than among better off women (Podhisita et al. 1994). If these socioeconomic differentials in behavior translate into similar differences in levels of HIV infection, older persons of low socioeconomic status will likely suffer a disproportionately high probability of experiencing the death of an adult child to AIDS.

Age, sex, and marital status are also closely linked with behaviors that put one at risk for HIV and AIDS. As discussed above, most sex patrons are young unmarried men, but many of these men who are infected while single will be married by the time they become ill; many women will subsequently become infected through their marriage partners. The implications of sex (male versus female) and marital status of PWAs for their older parents is discussed further below.

Biological factors will also influence which young adults become infected, and, in turn, which older persons are affected, either directly or by interacting with sociocultural and behavioral factors. Some families may be predisposed to or protected from infection through genetic factors (Kimani 1998). Individuals, families, and communities with poor access to STD treatment may as a consequence be at heightened risk for HIV acquisition. Families that do not practice circumcision may be at higher risk of having a young adult contract AIDS than families that do (Caldwell and Caldwell 1993).

The middle boxes in the bottom half of Figure 2 propose a relationship between the infection of a young adult and a variety of impacts upon his older parent(s). Older persons may face a variety of financial difficulties as a result of their child contracting HIV and developing AIDS. First, the older person may need to liquidate their financial assets for the living and medical expenses of PWA family members. In some cases the older person may need to stop or curtail working in order to help care for the PWA; this could have serious negative consequences for the financial wellbeing of the older person. Funeral expenses for the PWA, which can be very significant in Thailand, may need to be covered by the older parent. These financial burdens are likely to be greatest for the older person when the PWA coresides with him or her, either because the PWA has always lived at home, or has decided to return home to live after becoming ill. If the

PWA was already coresident before becoming ill, then the loss of labor or income formerly contributed by the PWA to the older person's household will have negative consequences for the older person. If the PWA and his/her family return home to live with the older person, then the increased household size will result in the additional consumption of food, clothing, and other household goods. For example, schooling costs for the older person's grandchildren may need to be provided from the assets of the older person. If the PWA had been sending remittances home before becoming ill, then the discontinuation of these remittances may have negative impacts for the older person unless others (e.g., siblings of the PWA) are available to make up for this lost income.

The next set of micro level effects in Figure 2 address the potential health impacts upon the older person should a PWA child live with the older person. In some cases, the older person may need to return to work in order to provide for some of the expenses described above, and this could have a negative impact upon the older person's health. If the older person is providing some of the care giving for the PWA, the physical strains involved (e.g., needing to lift the PWA) may injure the older person. Related to this, if the older person is not well informed about the handling of infectious fluids and wastes (or if the older person does know about the risks but does not want to take precautions in order to avoid the impression of fear or disgust of the sick child), then exposure to the HIV virus constitutes a health threat. Physical exhaustion resulting from care taking strains may also occur for some older persons caring for PWAs.

The next sets of effects focus on the potential time, social, and emotional impacts for an older person caring for a PWA child. The burden of care giving is likely to restrict the time the older person has available for other activities, including time that could be used for income generation and/or leisure. These opportunity costs of care giving will not only potentially affect the older person's financial status (as discussed above), but may also prevent the older person from fulfilling other social obligations and otherwise affect overall quality of life. Socially, older persons could potentially be alienated from their community should a PWA child come to live with the older person, and should other members of the older person's community have some fears or misgivings about a PWA living near them. The emotional strain associated with having to care for a child with a terminal illness will be difficult to assess and quantify, but existing research suggests that it will be devastating in many cases. The emotional toll on parents resulting from the loss of a child is extraordinary (De Vries, Lana, and Falck 1994; Sanders 1989). One study of stress among elders living in California found that the loss of a child was the most traumatic of all the stressful events measured (Aldwin 1990). This misery is compounded in many cases for the parents of PWAs, since the disease strikes in the prime of life, and because

its victims often suffer debilitating illness for long periods of time before dying (Mullan 1998; Brown and Sankar, 1998).

The link between the infection of a young adult and the proposed micro level effects on older persons will be moderated by a number of factors. Of course the first moderating factor is whether the PWA has any surviving parents. Second, this link will be moderated by patterns of extended family living arrangements (described above), remittance, and return behavior among PWAs.

Older persons living in rural areas are more likely to receive funds from non-coresident children than are older persons living in urban areas; also, daughters are modestly more likely than sons to remit funds to parents and to visit them (Knodel et al. in press). It is not yet known whether similar differentials may exist for return behavior (i.e., when PWAs become ill), but important interactions between sex and marital status appear likely.

Among married Thai couples afflicted by AIDS, the husband is usually infected first and so will in most cases become ill and die before his wife does. In cases where one spouse becomes ill (often the husband), the healthy spouse (often the wife) will frequently be the principal care giver. When the surviving spouse (often the wife) becomes ill, she may be likely to return home since she will have no remaining spouse to care for her.

For single PWAs, we expect that both men and women who become ill are about equally likely to return home for care, since they may have no one else available to look after them. The closer contacts (financial and otherwise) between older parents living in rural areas and their children (compared to older parents living in urban areas and their children) may make it more likely for children with parents in rural areas to return home than children with parents in urban areas. If true, then older persons living in rural areas may be responsible for disproportionately more of the PWA care taking burden than older persons living in urban areas.

The final link in the model connects the micro level effects of having an adult child with AIDS on older persons and the well being of the older person; this link will also be subject to important moderating influences. First, the nature and level of social and community response will moderate the degree to which these effects influence the overall well being of an affected older person. These responses are likely to vary by location. Areas that experience the highest levels of infection may benefit from increased attention by the government and non-governmental agencies, resulting in special programs that seek to alleviate the financial, social, health, and emotional impacts described above. On the other hand, afflicted families may also suffer from government and donor fatigue in these hardest hit areas. Similarly, the amount of

sympathy and community support given to PWAs and their families will likely vary by region, degree of urbanization, level of prevalence, and duration of the epidemic. Social stigma, for example, may decline over time in a locality and thus could be much worse in areas that are only recently experiencing an increase in AIDS cases compared to areas with more experience with the disease.

Second, some older persons will be in better position to cope with these hardships than others. As noted above, some affected older persons may return to work themselves to help pay for their own needs, the needs of an infected child, and/or the child's dependents. Thus, returning to work by an affected older person can be both a potential impact and a potential moderating factor. The degree to which returning to work is an option will in turn depend upon the skills, opportunities, and health status of the affected older persons. Socioeconomic status is also likely to be closely linked with the number and types of financial options available to affected older persons. For families living on the margin of poverty, if an adult child who was the main breadwinner for the family becomes incapacitated by AIDS, the consequences could be devastating for the older persons (and the PWA's other dependents) who rely upon this individual for financial support. These consequences may be mitigated in many cases if other adult children are available to replace at least some of the income formerly provided to the older person by the PWA.

Third, the degree to which PWAs have access to good-quality and affordable health care will likely affect not only the PWA but also his or her parents in a number of ways. Current data indicate that health conditions in Thailand are generally good. Life expectancy is 69 years, and the infant mortality rate is 29 (UN 1998). Both of these measures are favorable by middle income standards, and suggest widespread access to health care. Indeed, the UN estimates that 90% of Thais have access to health care services (UN 1997). But as elsewhere, there is variation among subgroups, and more importantly for our interests, these variations could affect the degree to which AIDS might impact some older persons more than others.

Health care is available for Thais within both public and private systems. The public system consists of community-based health stations located throughout rural areas and a network of hospitals located in the towns and cities. The private system is considered by many consumers to be superior in quality and convenience, but not all have equal access to it. Thais who access the private system usually do so in urban areas, since incomes are higher there (which allows more urbanites to use the more expensive private system if they choose), and because most private practitioners choose to locate in urban areas.

These differentials in health care access have several implications. First, among Thai families having a PWA, it will be the financially better off and those living in urban areas who will have access to AIDS treatment regimens beyond the basic maintenance approach provided by the government system.<sup>8</sup> Second, poor families will be the least able to hire outside assistance to help care for the sick child,<sup>9</sup> although rural villagers may have better access to networks of unpaid potential care givers than do day laborers working in urban areas. Third, as noted above, many of the poor will not be able to afford advanced treatments that will be available to more privileged families. But this also implies that it will be the better off families (the middle class and the wealthy) who are most likely to face the consequences of significant outlays of funds for treatment.<sup>10</sup>

Fourth, the availability of assistance for health care expenses could affect the degree of burden experienced by affected families, especially poor families. In Thailand, there are several groups who receive free or subsidized health care. The public system provides free health care to older persons. The destitute have their health care costs covered by the government system. Employees in the private sector who pay into the government's social security system have their health costs covered by this system. Civil servants have their health costs covered if they use the public system. Perhaps most significantly, families can buy a health card for B500 (\$15)/year that provides almost unlimited access to the public system, albeit for limited services.<sup>11</sup>

In addition to these various forms of health care coverage, there are publicly sponsored programs available to some groups that could be used to defray health care costs. There is a general welfare system for the poor that is run by the Department of Public Welfare. There is also a special welfare program run by this office that provides B500 (\$15)/month to a limited number of PWAs or to their families who care for them. The number of these welfare

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<sup>8</sup> Regarding treatment for AIDS, Westley (1999) reports that opportunistic infections are treated in government hospitals and clinics, but only pregnant women receive retroviral treatment. Dr. Chaiyos Kunanusont, Director of AIDS Division, Thai Ministry of Public Health concurs that AZT is available in many provinces to help prevent mother to child transmission, and that most PWAs (other than HIV positive pregnant women) do not receive antivirals. Combination therapy is taken by some PWAs in northern provinces. Although some of the least expensive preventive treatments (e.g., co-trimoxazole for PCP and isoniazid for TB) are available, not many PWAs return regularly for follow up treatment, so use of these drugs is not consistent (personal communication, September 1999).

<sup>9</sup> In Thailand, hiring outsiders to help care for the sick appears to be a rare occurrence, but this may be more common in other high prevalence developing countries.

<sup>10</sup> Better off families are also likely to feel compelled to have more elaborate and expensive funeral arrangements than those who are less well off, and will realize a more significant loss from these expenses.

<sup>11</sup> Due to the ongoing economic crisis in Thailand, the list of essential drugs covered by the health card was revised in January 1999. Since this revision, many hospitals have reduced the number of drugs they provide as part of health card coverage. This change has especially affected the treatment of PWAs who are dependent upon the health card.

allowances varies by province, and tends to be particularly high in the very high prevalence provinces of the upper north. However, this system seems not well utilized in many provinces outside of the north, even where AIDS levels are moderately high. One key barrier is that PWAs and their families are less open about AIDS outside of the upper north and thus may hesitate to ask for public assistance that would call attention to their situation.

Pensions are another potential source of revenue for paying the health care costs of PWA family members, but at this point in time, few older persons in Thailand other than retired civil servants receive such pensions. The newly instituted social security system will eventually provide retirement benefits to the additional groups who pay into it, but such payments are not scheduled to start for at least another decade.

Access to these assistance and retirement programs has clear implications for the degree of burden taken on by older persons who care for PWAs. For PWAs and/or their families who are eligible for (and who know about) public health care, other types of subsidized health care, and retirement benefits, these programs can serve to reduce the financial burden of health care (and other) costs involved in the support of the PWA. These subsidies can put health care within reach of the poor who would otherwise be little able to afford even basic treatments for their PWA family members.

#### KEY ISSUES FOR STUDY

AIDS affects older persons in a variety of ways, many of them closely interconnected. For example, the degree of financial burden experienced by an older person having an adult child with AIDS will depend upon the care taking arrangements made for the PWA. These care taking arrangements in turn depend in part upon the structure of the PWA's and the older person's households. These household structures in turn are affected by patterns of return behavior. Return behavior in turn may be influenced by the degree of social stigma in the older person's home community. Thus, we believe that studies that seek to assess the impact of AIDS on older persons should focus on a set of related demographic and social phenomena, although we acknowledge that assessing such a wide variety of issues presents formidable methodological challenges. In this final section of the paper, we outline what we are finding to be some of the most productive substantive areas of inquiry on this topic, and we discuss the potential advantages and limitations of data collection and analysis strategies that can be used to investigate them. We are aware that each setting will have unique characteristics; our objective in this section is to draw upon our own experiences in planning and

implementing our current study in the hope that some of the lessons we have learned will be relevant for others who are planning similar work.

## *Research Questions*

The specific questions to be explored in a study of the impact of AIDS upon older persons will of course depend upon the interests of the research team and the characteristics of the population of interest. In this section we suggest a number of topics that investigators may wish to consider as general research areas. We divide these topics according to whether the impacts upon the older population are direct (the older person is infected) or indirect (the older person is affected via the infection of significant others).

### Direct effects of AIDS upon older persons

Older persons are not among those considered to be at particularly high risk of contracting HIV. But there are indications that infection levels among older persons in the United States are higher than previously thought, and activists and health officials there are beginning to pay much more attention to older PWAs (Gross 1997). Given the substantial lag between initial infection and onset of symptomatic AIDS, risk behavior at ages below 50 can lead to AIDS-related illness after age 50. Thus even if few older persons engage in risk behavior, a substantial number may become ill as a result of risk behavior and infection at younger ages. Also, as therapies that extend the survival of HIV positive persons become available and more widely adopted, more PWAs will be surviving to older ages, at least in developed countries like the U.S. (Ory, Zablotsky and Crystal 1998).

There is a growing research literature on older persons who may be at risk of contracting AIDS or who already have done so (e.g., Editor 1998); older populations in some developing countries may warrant additional attention. Research on the direct effects of HIV on the older population could include the following topics:

1. What are the levels of infection among older persons? In Thailand and in many other developing countries, sophisticated models estimate the numbers of persons infected with HIV, but very little effort has gone towards determining whether the age distribution generated by these models accurately reflects infection levels among persons age 50 and over. The fact that very few AIDS cases have been reported among Thai older persons is not reassuring: older infected persons presenting symptoms typical of AIDS may be less readily identified as PWAs than younger patients if physicians and other health workers do not see older persons to be at risk of infection.
2. What types of risk behaviors might some older persons be engaging in? Little is known about the sexual practices of older adults, but it is possible that some older individuals engage in behaviors that may expose them to the virus.

For example, Thai men who had their earliest sexual experiences with sex workers may return to this behavior pattern if they become separated or widowed, or if their spouse becomes disinterested in sex. Hypotheses such as this should be empirically assessed.

3. Do older PWAs differ from younger PWAs? Are some groups of older persons more at risk than others? Do older persons contract HIV in ways that are similar or atypical for younger PWAs? Are the symptomology and optimal treatment regimens comparable? We know little about the epidemiology of or the prognosis for HIV infection among older persons, especially in developing countries.
4. What are the typical care taking arrangements for older PWAs? Will spouses, old themselves, be able to handle the rigors of care taking for older persons who come down with AIDS? Who cares for older PWAs who do not have a spouse available for care giving? What are the consequences for the care givers?
5. To what extent do older persons know how to avoid infection with HIV? There have been numerous efforts to assess AIDS knowledge within the young adult populations that are at greatest risk for contracting HIV and AIDS, but we know little about the extent of older persons' knowledge about this virus and disease.

#### Indirect effects of AIDS upon older persons

Since older persons are at lower risk for contracting HIV and AIDS than are younger persons, it will be the *indirect* effects of AIDS that will affect the older population the most. That is, most older persons who experience the ill effects of the AIDS epidemic will do so because of the infection of other (usually younger) family members, rather than because of their own infection. These indirect impacts, outlined earlier in the paper, imply several potentially productive areas of research.

1. What number and proportion of older persons will lose an adult child to AIDS?
2. What are the typical living arrangements of PWAs, and what are the implications of these living arrangements for older persons? For example, what proportion of older persons currently live with a child who will develop AIDS? What proportion of older persons with children living away from home will have a child ill with AIDS move back home to live with them?
3. How often do older persons provide care for ill PWAs? What types of care taking are required? What do older persons know about proper and safe care giving procedures for PWAs? Is their knowledge of the disease adequate

to make informed decisions on behalf of the PWAs under their supervision to ensure that the latter receive appropriate treatment from health providers?

4. What are the financial, social, health, emotional, and time impacts upon older persons who experience a child dying from AIDS?
5. Are some groups of older persons more likely to be affected by an AIDS death to an adult child than others? If yes, what are the characteristics by which these groups can be most meaningfully defined?
6. How frequently do older persons foster orphaned grandchildren? What types of care are required? What are the impacts upon the older person's health, daily routines, and financial status?
7. How do local communities react to PWAs and their families when PWAs become ill in the village or urban community, or when they return to their home communities for care taking after becoming ill? How are their older parents and surviving children treated after the PWA dies?

### *Methodological Approaches*

The research questions suggested above require a variety of methodological strategies for data collection and estimation. Even a single topic sometimes requires a combination of approaches to obtain a reliable assessment. For example, many PWAs are likely to change their living and care taking arrangements during the course of their illness. Thus the characterization of these arrangements provided by any particular source will depend upon the stage of illness to which the source refers. If a source is familiar with only PWAs who are at early stages of their illness, the extent to which parents are involved in care taking will be understated. A complete picture of the extent to which PWAs return to parents for care will only be evident for PWAs who have died. Moreover, particular sources used to investigate the living and care taking arrangements for PWAs may be selective of particular types of PWAs (e.g. PWAs who attend organized groups or PWAs who receive welfare), and so may be systematically biased towards particular arrangements. Thus any single source of information by itself may not be generally representative. Information from different sources must often be cross checked with each other in order to obtain the most comprehensive picture of the overall situation.

In this section we draw on our experience from our current research to discuss several types of data sources and approaches to data collection that could be used to study the impact of AIDS on older people in developing countries. We highlight the objectives served by each source and method along with their respective advantages and limitations.



### Official statistics

The Thai government maintains several official databases that can be used to help estimate some of the direct and indirect impacts of AIDS on the older population, and other countries may maintain similar types of information. The official tabulations of PWAs by age can provide a lower bound or a minimum number of older persons infected with HIV. To derive more accurate estimates of the numbers of older persons with AIDS, these official figures will need to be inflated according to the extent of the overall undercount of PWAs counted in official statistics, and then further adjusted if it is found that older persons are differentially missed by official statistics compared to other age groups. The age distribution of reported AIDS cases can also be useful as input data for projections or simulations conducted to estimate future numbers of AIDS cases by age. Official statistics maintained by the government may also include background characteristics that could be useful in determining the epidemiological risk factors for older persons vis a vis younger adults, and could be used to help target the hardest hit areas and groups for interventions.

### Surveys of older populations

As developing countries become more cognizant of the growing numbers of older persons in their populations, many have conducted surveys to assess the characteristics of their senior members. Thailand, for example, has completed several of these surveys, including information on living arrangements, economic transfers, and contact with kin (Knodel et al., in press). These data can be used to provide baseline information about the proportion of young adults who live with older parents, which can then be compared to the living arrangements of persons ill with or dead from AIDS. Such a comparison can help reveal the extent of return migration that occurs when young persons become ill with AIDS. These surveys of older populations can also provide baseline measures of the extent and amounts of financial support that older persons receive from their adult children, which can in turn be used to help predict the consequences that could occur if this support is cut off. Finally, some of these surveys may contain limited information on sexual behavior among older persons.

Elderly surveys conducted to date have the advantages of often being national in scope, being professionally conducted by prestigious research centers, and having large random samples. Unfortunately, surveys of older populations have not yet been conducted in many of the developing countries most seriously affected by AIDS.

In addition to surveys of older persons, other social surveys of more general populations typically include information on household information and may even have information about the surviving parents of the survey respondents. Household composition data from such surveys, for example, can be used in combination with epidemiological data to help determine the likelihood of a young person contracting AIDS while living with an older parent. These more general surveys can also help provide baseline estimates of the frequency of various living arrangements, which would in turn help assess migration behavior of PWAs returning home when ill.

#### Demographic estimations and simulations

Techniques of demographic estimation as well as more complex micro-simulations can be used to predict the number of older persons who have an adult child who will develop AIDS; who have an adult child living at home who will later develop AIDS; and who have a non resident child who will develop AIDS and return to live with the older parent. While the details of such estimation techniques are well beyond the scope of this article, several points are worth highlighting. Results from surveys that provide information about the older population, combined with projections of the AIDS epidemic can provide input data for demographic estimation and micro-simulation exercises designed to answer the questions posed above. These estimates should incorporate appropriate competing mortality risks (for the older person, and for the adult child from non-AIDS causes), anticipated changes in mortality schedules (for older persons, their non-infected children, and/or for PWAs), and any anticipated changes in HIV prevalence rates. Estimates of AIDS mortality can be derived from AIDS projections that are often conducted for high prevalence countries. General mortality risks for adult children who do not die of AIDS as well as mortality risks for their parents can be computed from official mortality statistics or model life tables such as those used for standard population projections prepared by national governments or international agencies such as the UN.

Clearly such estimates are only as good as the input data used. In at least some countries experiencing substantial AIDS epidemics (Thailand among them), much prior effort has been invested in these AIDS projections; other required input data are available and of sufficient quality to provide reasonable estimates of the demographic magnitude of the indirect impacts of AIDS upon the older population.

#### Key informant interviews

The difficulty of locating sufficient numbers of cases combined with the sensitive nature of the subject matter pose serious challenges to quantitative studies of the impact of AIDS on the older parents of PWAs (Mullan 1998). One way to overcome these problems is to interview key informants who can serve as proxy respondents. Various types of key informants can provide the basic data for a number of essential measures. Since many developing countries have health facilities in the rural communities where the majority of the population lives, local health officials in these areas often have detailed knowledge about the living and care taking arrangements of PWAs living in their local communities. These key informants will sometimes also be aware of whether the PWA had been living in the area prior to becoming ill or had migrated back home after becoming ill. They may also have information regarding the degree of involvement of the older person in the care and support of the PWA.

Employing health professionals as key informants can also help maintain anonymity, since it allows for the gathering of potentially sensitive information without identifying the case by name and without visiting the affected individual's home. This may be especially important in areas where AIDS is associated with significant social stigma. Key informant interviews can also be conducive for probing issues that may be too sensitive to ask an affected family directly, e.g., the progression of symptoms, the severity of the case, etc. Knowledgeable key informants can provide both detailed quantitative as well as rich qualitative information about the case and its impact upon the PWA's family.<sup>12</sup> Finally, a key informant who is also a community leader is often in a privileged position to assess the local community reaction to the PWA and his family.

There are a number of potential drawbacks of a key informant strategy for data collection. First, this approach is heavily dependent upon the key informants' knowledge and their willingness to cooperate. Those who are not from the local area or who have only recently arrived at their post may not be able to identify AIDS cases in the area very completely. Also, the key informants may not be knowledgeable about the specific details of all the cases that they can identify. Record keeping practices and the general competence of informants vary from locale to locale. Some key informants may base their comments upon preconceptions or stereotypes rather than actual knowledge of the case. For example, if the key informant believes that in most cases it is the mother rather than the father who *generally* provides care to ill children, the key informant may report this as a fact for cases in which this information is not really known. A

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<sup>12</sup> We use a standardized form to record the responses to most of our queries to the key informant, but we also record and transcribe the interview in order to extract rich qualitative data. For example, a key informant will often describe in poignant detail how difficult a particular case was for the older person, or the nuances of community reaction to a case.

skilled interviewer can help minimize some of these problems; indeed, much time and effort must be invested in the selection and training of key informant interviewers. This dependence upon skilled interviewers also implies that the quality of the data is likely to vary with both the skill of the interviewer and the knowledge of the informant.

A second potential drawback of the key informant approach stems from the fact that it is typically easier to find knowledgeable key informants in rural areas than in urban areas, due to the greater degree of shared knowledge in villages compared to towns and cities. It is our experience that urban health personnel generally have no where near the same degree of familiarity with the community that rural health station staff have. This can bias results if urban settings are not adequately represented. For example, if data collected in rural areas about PWA migrants who return home from cities after becoming ill are fairly complete, but information collected in cities about PWA urban migrants who do not return home is incomplete, then estimates based upon these data will overstate the extent to which PWAs return to their parents living in their home villages.

We address this problem of potential selection bias in our own research in the following manner. In Bangkok, we collect data on individual PWAs from key informants at a very local level covering far fewer households per local site than in the rural areas. We also expand the range of informants whom we interview to include local health volunteers and community officers who are more likely to be familiar with the situation at the local site, including information about transient community members, than would government health workers at hospitals and health stations that serve broader publics. Moreover, we also interview staff members of major organizations assisting large numbers of PWAs in Bangkok. These staff members report that of the PWAs they come into contact with, most PWAs originally from rural areas eventually return home, especially once they become too ill to work. Thus the risk of this particular bias seems to be minimal in Thailand, although the situation could be very different elsewhere.

In brief, although there are drawbacks inherent to the key informant approach, we believe these drawbacks can be minimized through careful research design and interview skills. Moreover, these drawbacks must be weighted against the biases likely to result from samples based on volunteers or self identified cases, especially in the context of a stigmatized disease such as AIDS (Levy and Albrecht, 1989). The key informant approach has the potential to yield more accurate results.

### Surveys of PWAs

A second method to gather information about the living and care taking arrangements of PWAs, especially in urban areas, is to survey them directly via PWA support groups. Either self-administered questionnaires or face-to-face interviews could be used for this purpose. Such surveys can inquire about current as well as plans for future living and care taking arrangements, and the extent to which these current situations and plans involve older persons. One advantage of this approach is that it surveys directly those most familiar with their own situation and perhaps best able to predict what their future course of action will be. A second advantage is that the PWA survey provides an additional data source from which to study the difficult-to-access urban scene.

A shortcoming of a PWA survey involves the difficulty of recruiting a representative sample of respondents. For example, a likely strategy for such a survey would be to recruit respondents through PWA groups. However, such a sample is likely to suffer from selectivity biases including those stemming from the fact that the PWAs who belong to these groups and attend their meetings are limited to those who are healthy enough to do so and thus would not yet have serious care taking requirements. Such a subgroup of PWAs may not yet have thought carefully about their future plans. PWAs who join and attend PWA support groups may differ in other important ways (in addition to stage of illness) from PWAs who do not. For example, PWAs who join support groups and attend meetings may be more open about their HIV status than PWAs who do not. Related to this, PWAs who are more open about their HIV status may have available to them more options for care taking and living arrangements than PWAs who are not willing to publicly acknowledge their condition.

#### Open-ended interviews with older persons affected by AIDS

Open-ended qualitative interviews of older persons who have experienced the loss of a child to AIDS can provide valuable information about the impacts of an AIDS death if the interviews are conducted in a professional, sensitive, and compassionate manner. During the open-ended interview, respondents provide detailed and concrete examples of the emotional, physical and economic hardships associated with having an adult child die from AIDS. The in-depth and detailed information from these interviews can provide important insights for developing structured instruments such as survey questionnaires or key informant interview schedules that subsequently could be used to collect information from a larger and more systematic sample. In addition to providing insights about typical problems faced by older persons

with PWA adult children, these interviews also provide rich context and details about specific cases, information that cannot be elicited from a key informant or standard survey format.

It is usually necessary to employ an intermediary to identify potential respondents and make initial contact about their willingness to be interviewed. Such prior screening has distinct ethical and logistical advantages. Nevertheless, the potential selection biases this procedure introduces must be considered during the interpretation of the results.

A second drawback of open ended interviews with older persons is the anguish that can arise for both the respondents and interviewer as this information is conveyed. Our experience so far suggests that there are many older persons losing an adult child to AIDS who are very willing to talk to us about their situation. Of course it is difficult to generalize on this point since we have no data from those whom do not wish to be interviewed or whom our intermediaries assumed would not wish to be interviewed. Among those we have interviewed, all have been willing to discuss their experience of child loss with us, albeit with a range of emotional responses to the interview. Some do not seem overly disturbed by the discussion. Others want to share their grief with a sympathetic listener. A few have become quite upset during the interview. We feel that a skilled interviewer can in fact provide some level of comfort to the family as a byproduct of the data collection. Still, the risk of causing distress to some respondents is real and must be weighed carefully.

#### Knowledge, attitudes, and practices (KAP) survey of older persons

Numerous studies of AIDS-related knowledge, attitudes, and practices among members of high risk groups have been conducted in both developed and developing countries. Older persons have not typically been included in these studies since they have not been considered to be at high risk of contracting HIV and AIDS. But it is possible that there may be more older persons engaging in risky sexual behaviors than previously thought. More importantly for countries experiencing high levels of HIV infection among young adults, a large number of older persons will be providing care to family members who become ill with AIDS. Yet we know very little about the extent of knowledge older persons have about AIDS, especially regarding the care giving requirements of PWAs, modes of HIV transmission through improper care giving practices, and the extent of unreasonable fears older persons may have about contracting AIDS via casual contact. A primary advantage of this data collection strategy is that it is a fairly straightforward way to assess the behaviors, attitudes, and practices of a group that will have increasing exposure to PWAs and AIDS in the near future.

Since the target group on which such a study would focus is not specifically families impacted by AIDS, we can avoid the potential biases that complicate some of our other data collection strategies.

There are special considerations one should take into account when conducting an AIDS KAP survey for older persons. Questions relating to PWA care giving and the risks of infection among older persons need to be developed that fit the special needs, experiences, and sensitivities of this particular population. These new questions should be pre-tested carefully to ensure ease of comprehension by respondents; these newly developed questionnaire items should also be assessed for validity and reliability.

### Surveys of Older Persons Affected by AIDS

To fully assess the impact of an adult child death due to AIDS upon his or her older parents, we can conceive of no adequate substitute for direct surveys of older persons who experience these unfortunate events. Such surveys are most likely to employ structured questionnaires and face-to-face interviews. The questionnaire would be designed to assess the major economic, social, physical, and emotional impacts for older persons that result from an AIDS death to an adult child in the older person's family.

Such a survey faces a number of formidable barriers. First, since the potential impacts are so diverse and in many cases so severe, the need to develop an instrument that adequately explores each dimension without over burdening the respondent poses a substantial challenge. Second, one must specify the appropriate reference group required to assess the impact of an AIDS death, i.e., an AIDS death to an adult child has a series of impacts upon an older person compared to what other type(s) of scenario(s)?<sup>13</sup> Third, the sensitivity of the topic will demand great interviewer skill. Fourth, since young adult deaths, including those due to AIDS, are rare (and sometimes very private) occurrences, obtaining a population-based sample of sufficient size will require considerable time and effort. One strategy is to identify families through local key informants. This carries the risk, however, that such informants are likely to have more complete knowledge about parents whose adult child died locally than cases where then when the adult child died elsewhere. This can bias results since the impact of these two situations on the parents is likely to differ. Related to this, families who decline to participate are likely to be quite different from families who agree in a number of important

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<sup>13</sup> One attempt to specify appropriate reference groups included three types of situations: older persons experiencing a child dying of AIDS; older persons experiencing a child dying from another cause; and older persons experiencing no child death (Pitayanon et al. 1997).

dimensions related to our dependent variables of interest. Fourth, although a family may be willing to participate, it may deny that the cause of death of their child or relative was AIDS, making it difficult to ask the pertinent questions regarding an AIDS death, e.g. questions about community reaction. Our experience in Thailand suggests that, if cases of parents who lose a child from AIDS can be identified reliably from some external source such as key informants in the health sector, problems associated with parents not wanting to admit that their child had AIDS can be reduced substantially by not referring to the child's disease as AIDS during the interview, but in terms preferred by the respondent.

## CONCLUSIONS

Older populations in many developing countries will face considerable hardships in the coming decades because of AIDS. While it is likely that some older persons will become infected with the HIV virus themselves, many more will face financial and care taking responsibilities for their infected children. Other hardships, such as grief, care for orphaned grandchildren, negative community reaction, and disruption of remittances and other types of support from the ill child, are also likely to occur. These indirect impacts of AIDS upon older persons have not been adequately explored, either conceptually or empirically. We have proposed a model for examining these effects, and draw upon our current study on the impact of AIDS on the Thai older population to illustrate potential research strategies for addressing this important topic.

Figure 1: Projected numbers of AIDS deaths. Source: NESDB 1994.

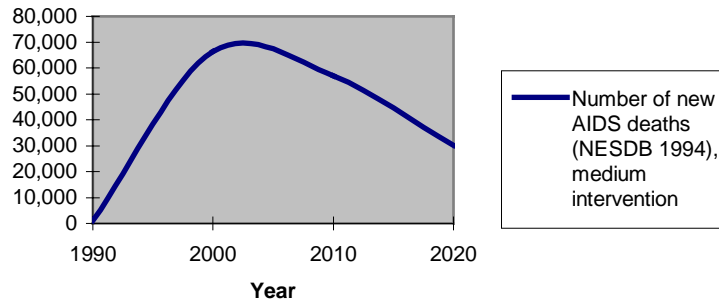
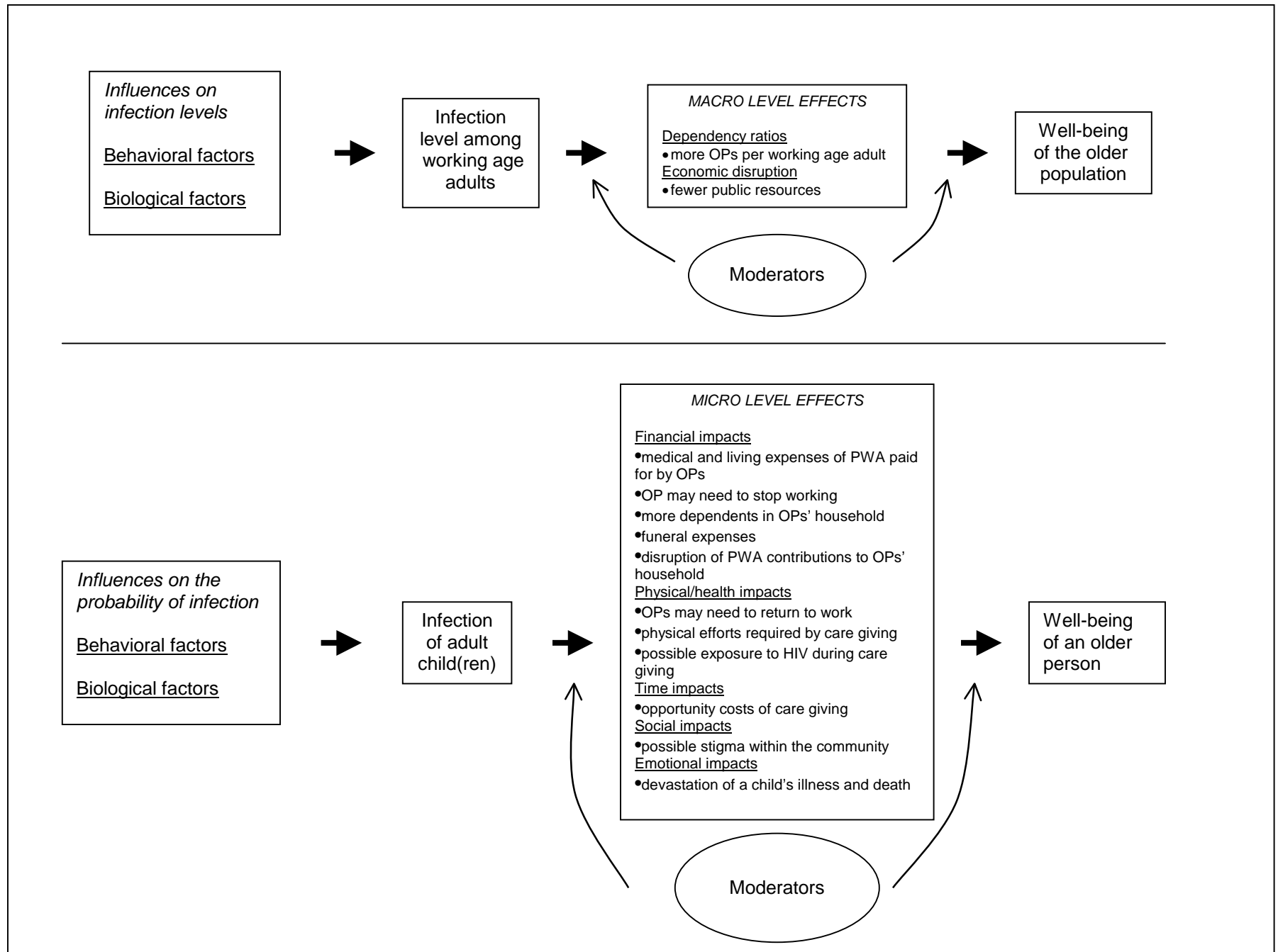


Figure 2: Potential Mechanisms: Indirect Impacts of the AIDS Epidemic on Thai Older Persons (OPs)



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