

PARENTS OF PERSONS WITH AIDS: UNRECOGNIZED CONTRIBUTIONS AND UNMET NEEDS

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The global AIDS epidemic is well into its third decade with over 25 million deaths attributed to it (Advert, 2006). Another 40 million persons are currently infected (UNAIDS/World Health Organization, 2005). The impact of the epidemic, however, extends well beyond those infected with the virus. Family members are particularly vulnerable and may be adversely affected emotionally, economically, socially, and physically. Most who become infected and die are in their adult ages. Much attention has been directed at the plight of AIDS orphans, the young children left behind. Most adults with AIDS also have parents who, typically, are approaching or already in their older years, and who can be profoundly affected by their adult child's illness and death. Yet these AIDS parents—the mothers and fathers of AIDS victims—are largely absent in the discourse about the epidemic, other than as grandparents who foster AIDS orphans. Only belatedly is recognition starting to extend to their contribution to the home-based care of their terminally ill adult sons and daughters, especially in the developing world—partly a result of being highlighted at the United Nations Second World Assembly on Ageing in 2002 (United Nations, 2002). Still, with the noteworthy exception of HelpAge International, major organizations as well as national governments continue to ignore both the contribution and needs of older persons in relation to AIDS (HAI, 2006). Their low profile in the public discussion about the AIDS epidemic perpetuates the mistaken impression that older persons are largely outside its reach.

LARGE NUMBERS

Older adults are at risk of HIV infection. Indeed, the number of older HIV-infected persons will continue to grow as effective treatments that extend the survival of those infected at younger ages become more widely available. Still, persons over 50 constitute a relatively small share of the total caseload, particularly in the developing world (Knodel, Watkins, & VanLandingham, 2003). Far greater numbers of older persons, however, are impacted through the loss of an adult son or daughter to the disease. To realize just how sizeable the numbers are, one only has to recognize that the large majority of adults who die of AIDS have one or both parents surviving at the time of their deaths (Wachter, Knodel, & VanLandingham, 2002). Worldwide, the number of older parents who lost an adult son or daughter to AIDS is likely to be at least equal to the number of adults who died. Thus, the

number of AIDS parents is staggering, making the lack of attention they receive all the more regrettable.

PATHWAYS OF IMPACT

Older persons, especially in developing countries, can be adversely impacted through various pathways as parents of an adult son or daughter who becomes ill and dies from HIV/AIDS. Severe emotional distress over the child's suffering and decline during illness and long-lasting grief following the child's death are likely universal effects. The debilitating and often stigmatized nature of AIDS contributes to the emotional toll. Parents may also experience economic, health and social consequences. The potential impacts include financial difficulties emerging from a son's or daughter's illness, especially if the parents help with medical and living expenses, pay funeral costs, take responsibility for orphaned grandchildren, or curtail working to help care for the ill child. The loss of labor or income formerly contributed by the son or daughter can leave the parents in financial difficulty. The health of older parents could suffer through physical strains from caregiving and potential exposure to the opportunistic diseases (especially tuberculosis) that the ill child contracts (Valenti, 1995). Social and economic relationships may be severely disrupted by the time-consuming demands of caregiving and by the social stigma sometimes associated with the disease.

EVIDENCE FROM CAMBODIA AND THAILAND

One reason that AIDS parents are largely ignored in efforts dealing with the epidemic is that little research has focused on them. A small number of studies using participatory and qualitative research methods provide detailed insights into the experience of older members of HIV/AIDS affected households (HelpAge International, 2004 a, b, 2005; Saengtienchai & Knodel, 2001). Quantitative assessments of AIDS parents' contributions and needs are even rarer. This is especially unfortunate since policymakers and program managers, for whom the AIDS impact on older parents is but one of many issues, need to know the scale and not just the nature of the problem before they will be convinced that it deserves priority attention. Two important exceptions are research projects in Cambodia, one of the world's poorest countries, and Thailand, a middle income country.¹ Both provide systematic quantitative assessments of the contributions of older parents of adults who died of AIDS.

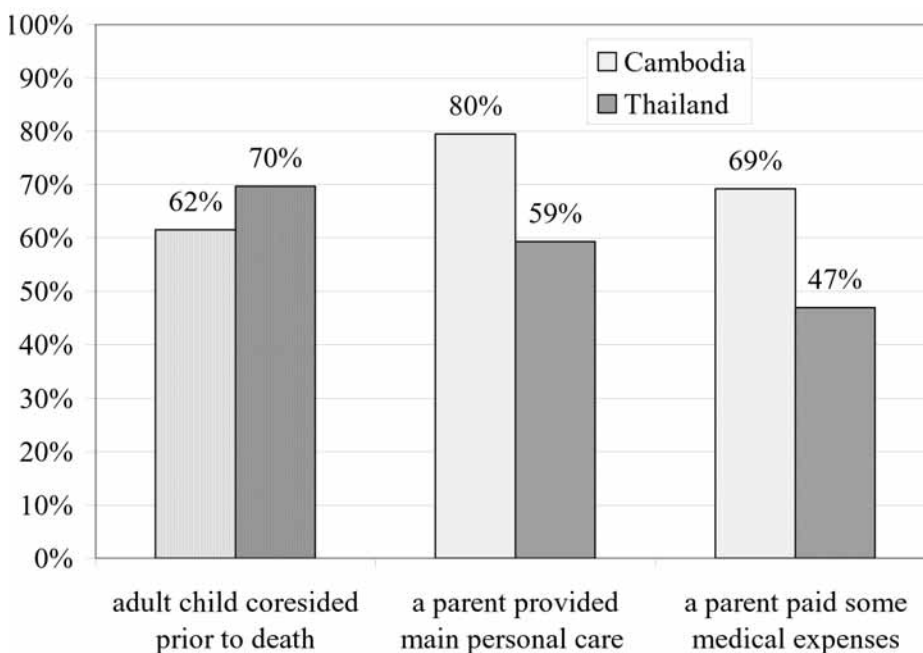
Jon Bugge/HelpAge International



Phon and her daughter-in-law, Thur, cared for Phon's son who died of AIDS. Phon looks after her grandchildren while Thur works for neighbours. (Cambodia, Battambang Province)

As Figure 1 shows, both Thai and Cambodian parents are commonly involved with their fatally ill children both through caregiving and shared living arrangements. Although Thai parents were somewhat more likely to share their living quarters with their child at the terminal stage of illness, parental caregiving and paying of medical expenses are more common in Cambodia than in Thailand, reflecting more extensive social protection measures in Thailand. For example, the Thai government provides health insurance that significantly offsets medical expenses for many Thai families affected by AIDS, and also sponsors modest welfare programs that specifically target persons with HIV/AIDS and their families. In contrast, government safety nets are almost totally absent in Cambodia.

Figure 1. Parental Co-residence, Caregiving and Expenses in Relation to an Adult Child Who Died of AIDS (Cambodia and Thailand)

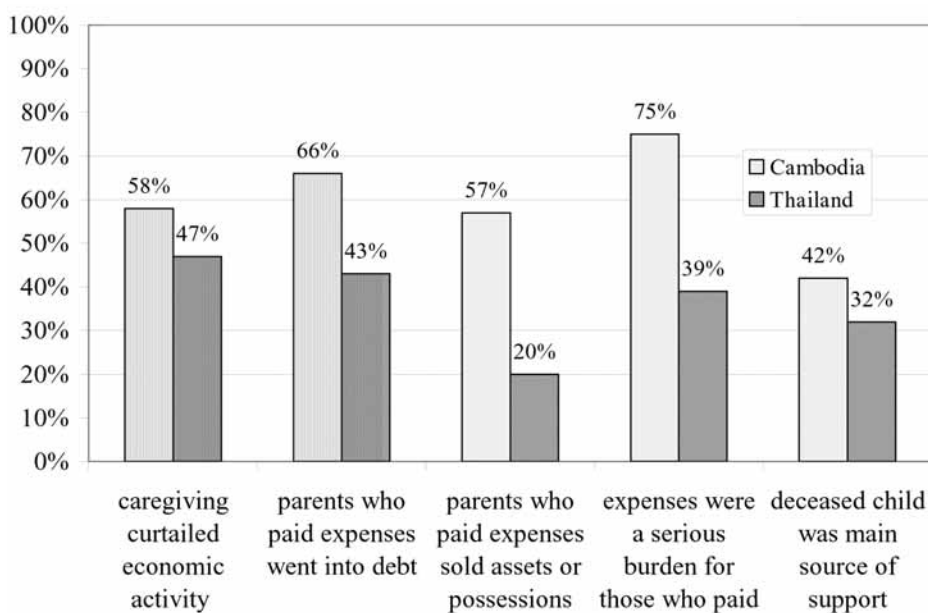


In both countries, more mothers than fathers provided the main personal care. In Thailand, the predominance of mothers as a main personal care provider was true even when both parents were alive at the time of their child's illness. In Cambodia, however, the predominance of mothers as main caregivers is solely the result of fewer fathers being alive to do so. In situations where both parents were still alive and living together, mothers and fathers were equally likely to provide the main care to their HIV-infected adult child.

The extensive involvement of parents in co-residence and caregiving in Cambodia and Thailand creates a situation in which the loss of an adult child to AIDS could involve serious direct and indirect costs as well as social consequences for the parents during the time of illness. Figure 2 illustrates some of the pathways through which the loss of a son or daughter to AIDS adversely affected parents' material well-being. In both, caregiving often interfered with the parents' ability to earn a living, forcing them to curtail their economic activity. Many parents did not have sufficient savings or cash in hand to cover expenses and, thus, were forced to go into debt or sell assets or possessions. This was considerably more common in Cambodia than in Thailand. Substantial proportions of parents who paid expenses said that it created a serious burden for them, although, again, considerably more so in Cambodia than Thailand. Longer term adverse implications for AIDS parents

are evident from the fact that for substantial minorities, the deceased child had been a main source of household support. The higher level of hardship and the more common borrowing of money and selling of assets to cover expenses reported in Cambodia likely reflect the more widespread poverty and weaker formal safety net there than in Thailand.

Figure 2. Consequences for Older Parents When an Adult Child Becomes Ill and Dies of AIDS (Cambodia and Thailand)



A substantial number of AIDS orphans in both countries are cared for by grandparents. However, in Thailand, about half of the adults who died of AIDS and over 40% of those in Cambodia had no dependent children. Moreover, although most AIDS orphans typically have both maternal and paternal grandparents who could care for them, only one set does so. As a result, the proportion of AIDS parents who actually care for AIDS orphans is modest and far lower than the proportion of AIDS parents who take care of their terminally ill sons and daughters. It is, thus, somewhat ironic that AIDS parents are mainly recognized in the role of fostering grandchildren and far less frequently as caregivers to their AIDS-infected adult children.

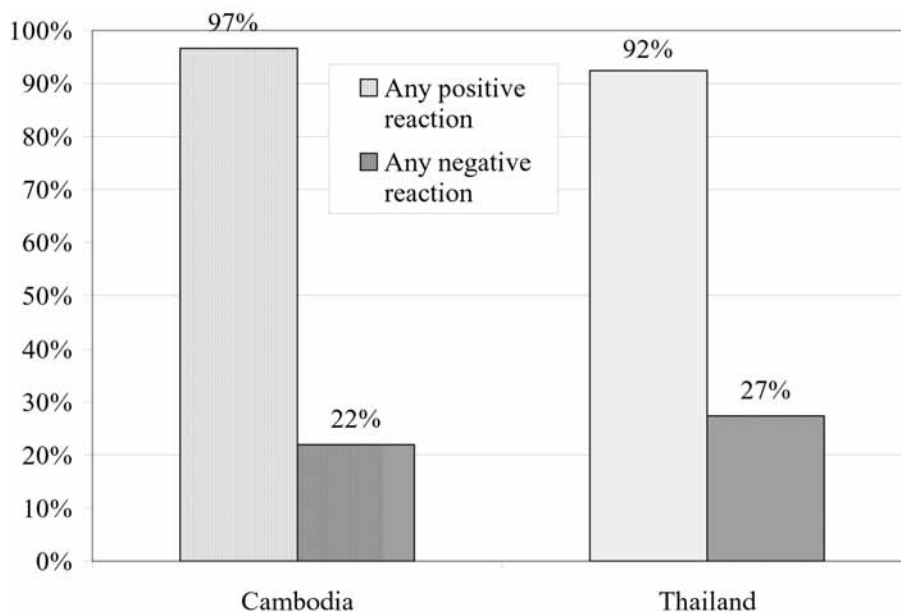


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Phat cares for her son, Vy, who is living with AIDS. (Cambodia, Battambang Province)

The stigmatization of AIDS appears to have declined substantially in both countries since the start of the epidemics. As Figure 3 shows, while negative community reactions towards parents of adults with AIDS are not absent, in Cambodia and Thailand, sympathetic and supportive reactions from neighbors are far more common than stigmatizing ones. This is attributable at least in part to widespread educational campaigns that have resulted in relatively accurate knowledge among much of the population, thus allaying fear of casual transmission. Also, commercial sex, a major route of transmission, has relatively little social stigma associated with it and, thus, those who become infected as a result of patronizing prostitutes and even providing sexual services do not evoke moral condemnation.

Figure 3. Community Reaction towards Older Parents during the Illness of an Adult with HIV/AIDS (Cambodia and Thailand)



The relative absence of strong and widespread stigmatization likely facilitates parents' willingness and ability to provide home-based care to their HIV-infected adult children as well as those who return at the terminal stage, having migrated from the parental home. It also suggests that there may be fewer barriers to community approaches to assisting older persons whose child becomes ill and dies of AIDS than would be assumed from the impression of hostility towards persons with AIDS commonly portrayed in the mass media and from the rhetoric of some advocacy organizations.

HINTS FROM ELSEWHERE

Cambodia and Thailand not only share a common border but also a common religion, Theravada Buddhism, which underlies many cultural practices and beliefs. Their political and economic histories, however, diverge sharply, especially in recent decades. While Thailand has been relatively stable and prosperous, Cambodia experienced civil strife, including the brutal reign of the Khmer Rouge in the 1970s when about a quarter of the population perished. These similarities and differences shape the way the AIDS epidemic impacts older persons and indicate that impacts depend on settings. It is important to gauge to what extent situations regarding AIDS parents elsewhere in the developing world correspond to those found in Thailand and Cambodia.

Tabulations from a 1995 survey in six districts of Uganda indicate that a parent was a primary caregiver for 48% of the almost 400 persons ill with AIDS. This corresponds closely to the estimated 50% of adults with AIDS in Thailand for whom a parent was a main caregiver (after taking cases into account in which no parent was alive). Equivalent systematic quantitative evidence is largely lacking for other settings. An earlier review of research, most of which referred to Africa and was typically qualitative in nature or based on extremely small samples, concluded that there is considerable congruence in pointing to older persons, and particularly parents, as being main players in caregiving to HIV-infected adults (Knodel & VanLandingham, 2002). A mixed methods study by the World Health Organization (2002) and other more recent research in Africa continue to confirm the crucial role of AIDS parents, although findings with regards to the favorable community reaction that seems to now predominate in Thailand and Cambodia are mixed (see e.g. Katapa, 2004; Chimwaza & Watkins, 2004).

OVERLOOKED POTENTIAL

The connection between older persons and AIDS merits emphasis, not only because of the adverse consequences AIDS parents likely suffer and the lack of programs to address them, but also because of the potential older parents have for improving the care of persons with AIDS. Our research indicates that parents often accompany their infected son or daughter to health service outlets, stay with them in the hospital, consult with health care providers about appropriate treatment, administer the prescribed medications, and provide a full range of personal care at home. They carry out these roles with remarkable determination and with almost unbounded desire to reduce the suffering and improve the health of their infected children. Similar patterns likely exist elsewhere in the developing world where the epidemic rages.

Older parents are ideally situated and motivated to help in efforts to improve the quality of care of persons with HIV/AIDS. Few could be as highly motivated as parents to help implement demanding new protocols of drug compliance, to encourage pregnant infected daughters or daughters-in-law to take the measures necessary to reduce peri-natal transmission, to help administer more aggressive treatments for opportunistic diseases, and to implement more proactive efforts to relieve pain and suffering among those stricken with AIDS. This potential is enhanced as new, more ambitious programs promote more extensive prophylaxis and treatment for opportunistic infections, complex antiretroviral treatment of HIV, and palliative care. Enlisting these parents in the front line effort to expand treatments will free limited health personnel to train and coordinate their actions, making possible a broader implementation of new programs than health personnel could administer alone.

CONCLUSIONS

The massive scale of the AIDS epidemic has transformed the mortality of adult sons and daughters in many areas hardest hit from previously rare events into common ones. Older parents have shouldered much of the burden of caregiving, financial strain, sorrow, and child rearing that have resulted from the epidemic. That they have done so in relative silence should not condemn them to continued neglect. An important implication of the high prevalence of parental caregiving and of the potential AIDS parents have for contributing to the response to the epidemic is that education campaigns should not just target younger adults, but also older persons, in order to ensure that the information provided relates not just to prevention, but also to caregiving. Likewise, intervention programs designed to ameliorate the social and economic impact on households need to incorporate the central involvement of parents of those infected and ill. Many older parents are in dire need of support on various fronts, and as we struggle to improve our response to the needs of the infected, we need parents' services to facilitate these efforts. AIDS parents need our help and we need theirs.

NOTE

- 1 A full bibliography of publications and reports is available at the project website, <http://aidseld.psc.isr.umich.edu/>. A detailed report of the Cambodian study is available at <http://www.psc.isr.umich.edu/pubs/pdf/rr06-594.pdf>.

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