

UNAIDS Case Study, November 2001. *Parents providing care to adult sons and daughters with HIV/AIDS in Thailand.*

As the worldwide HIV/AIDS epidemic continues, there is increasing recognition that more attention and resources need to be focused on those indirectly affected by the epidemic. Uninfected family members and significant others can be affected emotionally, economically, socially and physically by the illness and death of a person with AIDS. This is particularly true for persons who serve as caregivers. Much attention has been given to AIDS orphans—the children left behind by parents who have died from AIDS. Yet those with AIDS may not only have children but also parents who are affected in significant ways and who often act as caregivers to their infected adult children. None the less, almost no attention has been paid so far to the parents of those with AIDS, other than acknowledging their responsibility as grandparents who can care for their orphaned grandchildren. Their critical role as caregivers to their adult sons and daughters is typically overlooked because research on AIDS-related care giving in the developing world is not extensive. The studies that have been done, however, underscore the importance of the traditional family in providing care and support for adults with AIDS and, particularly, the major role that parents play. So far, the most extensive research that provides quantitative estimates is from Thailand. A study of approximately 750 individuals throughout the country who died of AIDS primarily between 1996 and 1999 indicates that parents—usually the mother—provided care, at least during the terminal stage, for almost two-thirds of the Thai adults who died of AIDS, and acted as primary caregivers for half.

This study provides a qualitative analysis of the circumstances and consequences of parental care giving to adult children with AIDS in Thailand based on open-ended interviews, primarily with parents of adult children who died of AIDS. The results reveal the circumstances that lead to parental care giving, the tasks involved and the stress they created, how parents coped with this stress, and the consequences for their emotional, social and economic well-being. The results make clear that routine care giving to those with AIDS often requires extensive time from the main caregiver. Care giving assistance is especially needed in the final stage of illness when the AIDS-afflicted person often requires help with even basic bodily needs and functions. Financial demands can also accumulate to the point where the adult son/daughter's and parents' own resources are exhausted. Such a situation can be overwhelming for anyone, but it is particularly so for an older person. With varying degrees of success, Thai parents often solicit the help of other family members in care giving, paying expenses and providing emotional support. In addition, viewing their role in terminal-stage care giving as part of the responsibility that parents have for their children (regardless of age), refusing to view the child as a burden, and avoiding blaming their son/daughter for becoming infected, all help Thai parents cope with the emotional stress of caring for their terminally ill son or daughter.

The experiences and consequences for parents of losing an adult child to AIDS are influenced in part by features relatively specific to the Thai setting but, at the same time, reflect conditions that are likely to be common to many other developing countries experiencing serious epidemics. Social stigma and the fear of it, while clearly evident in Thailand, are probably not as extreme as those reported for many other countries. Most of the stigma that exists seems to be based on fears of infection through association with a person with AIDS (and, much more rarely, their caregiver). One effect of this real or perceived stigma is that of inhibiting some parental caregivers from reaching beyond the family for emotional or other support, including taking full

advantage of the formal assistance that is available. Thus, continuing efforts are required to counteract this stigma and to reassure the public about the absence of risk of infection through casual contact. Information campaigns aimed at dispelling the misconceptions about risks, and promoting a sympathetic view towards those with AIDS and their informal caregivers, could help improve the situation.

Parents are often intimately involved in all facets of their adult children's experience with AIDS, as well as serving as a link to the health system and the community at large. In desperation, they frequently seek—sometimes at great effort and expense—treatments from practitioners of traditional medicine. Under these circumstances, parents need considerable guidance in care giving, including accurate and up-to-date information on availability and administration of appropriate medicines and treatments. Moreover, parents have a strong will to seek help for their child in any way possible. Thus, parents who are healthy enough to be mobile, within the community and beyond, have considerable potential to act as intermediaries between their infected or ill adult children and the health and welfare programmes of both governmental and nongovernmental organizations designed to serve those with HIV/AIDS.

So far, both the needs of parental caregivers and their potential in facilitating programmes directed at those with HIV/AIDS remain largely unrecognised. Older parents not only have great motivation and dedication to improve the well-being of their infected adult children but, in practice, are often the ones who accompany them to health service outlets, stay with them when they are hospitalised, administer prescribed medications at home, and act as major caregivers in general. Educational programmes on AIDS-related home care giving need to take into account the important role played by these parents. At the same time, the potential contribution parents can make to effective implementation of existing programmes should be harnessed. This could be particularly crucial if new programmes are launched to promote palliative care or to provide more extensive prophylaxis and treatment for opportunistic infections or complex antiretroviral treatment of HIV. Moreover, providing the means and knowledge for parents to administer more effective palliative care or to improve the prevention and treatment of opportunistic infections would help reduce parental distress to the extent that these measures reduce the suffering of their sick child. Improvements in HIV prevention and treatment would be of even greater benefit to parents, who ultimately wish to see their adult children continue to lead a healthy life.
