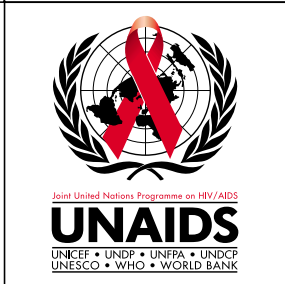




# Parents providing care to adult sons and daughters with HIV/AIDS in Thailand



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Cover photo:  
*Funeral procession for a young man who died of AIDS, Thailand.*  
Photo by John Knodel.

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# Parents providing care to adult sons and daughters with HIV/AIDS in Thailand



Joint United Nations Programme on HIV/AIDS  
**UNAIDS**  
UNICEF • UNDP • UNFPA • UNDCP  
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## Executive summary

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 caregiving 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 caregiving to adult

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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 caregiving, 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 caregiving to those with AIDS often requires extensive time from the main caregiver. Caregiving 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 caregiving, paying expenses and providing emotional support. In addition, viewing their role in terminal-stage caregiving 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 caregiving, 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 unrecognized. 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 hospitalized, admin-

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ister prescribed medications at home, and act as major caregivers in general. Educational programmes on AIDS-related home caregiving 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.

# I. Introduction

AIDS remains a debilitating and fatal illness in most developing countries. Although temporary periods of remission may occur following the onset of symptoms, eventual physical deterioration typically necessitates extended periods of intensive care. The need to understand the circumstances and consequences of caregiving for both AIDS-afflicted persons and their caregivers has spurred considerable research in the United States. Reflecting the fact that men having sex with men is the predominant mode of HIV transmission in the US, most such studies concern caregiving within the gay community (e.g. Folkman et al. 1994; LeBlanc, London and Aneshensel 1997; Turner and Catania 1997; Turner, Catania and Gagnon 1994; Turner, Pearlin and Mullan 1998). As studies on other chronically ill or impaired populations generally show, most caregiving is provided through informal social networks (Crystal and Schiller 1993; Folkman et al. 1994). In the case of AIDS caregiving, the US research often emphasizes the role played by persons outside the traditional family (e.g. partners and friends) as caregivers, reflecting the predominant focus on the gay community (Mullan 1998).

Research on AIDS-related caregiving in the developing world, where heterosexual transmission is the primary source of HIV, is not extensive. The most extensive research so far has been carried out in Thailand. Quantitative data based on approximately 750 adults throughout the country who died of AIDS primarily between 1996 and 1999 indicates that parents—usually the mother—provided care for almost two-thirds of the Thai adults who died of AIDS and acted as primary caregivers for half. The vast majority of

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these parents were aged 50 and over, and 40% were at least 60 (Knodel et al. 2001). A series of surveys in Uganda found similar levels of parental involvement as primary caregivers (Ntozi and Nakayiwa 1999). Qualitative research in Uganda and Ethiopia, and anecdotal evidence in Zimbabwe, also point to the important role of parents in caring for their AIDS-afflicted adult offspring (Gurmessa 1999; Mupedziswa 1997; Williams and Tumwekwase 1999).

While parental caregiving and support to adult offspring with AIDS is probably less common in the US than in most developing countries, the focus of US studies on currently ill persons, rather than on those who had already died, probably leads to underestimates of parental involvement. Living and caregiving arrangements often change during the course of the illness. Some adults who live away from their parental home at the onset of symptoms return for assistance only at the more advanced stages of illness (Brabant 1994; Ellis and Muschkin 1996; Sankar et al. 1998). The research in Thailand referred to in the previous paragraph indicates that 41% of adults who died of AIDS and who lived with or near a parent at the terminal stage had returned to their place of origin after becoming ill, often only when the illness was quite advanced (Knodel 2001). If a similar tendency to turn to parents for help at advanced stages of illness is present in the US, cross-sectional studies of current caregiving to persons living with AIDS would under-represent the extent to which parents eventually become involved.

The impact on parents of an adult son or daughter with AIDS, including their role as caregivers, has received very little research attention in either the US or elsewhere (Crystal and Schiller 1993; Dane 1991). A few qualitative studies in the US exist but they typically deal with a very

select group of parents—namely those who had a gay son and who were active in the AIDS movement (e.g. Brabant 1994; Dane 1991; Gregory and Longman 1992; Longman 1995; Peabody 1986). Most had told their story in public forums and thus are probably more adept at articulating their experiences than would generally be true for parents whose children had died of AIDS.

As others have stressed, the cultural milieu undoubtedly influences the nature of caregiving and the impact on the caregiver (Turner and Catania, 1997). This is particularly likely to hold true for AIDS since perceptions of the disease may differ substantially cross-culturally (Gregory and Longman 1992). At the same time, both in the US and elsewhere, a common distinguishing feature of parental caregiving to an adult son or daughter with AIDS is that it represents a reversal of the typical generational roles that characterize caregiving situations (Crystal and Schiller 1993). Thus important differences as well as similarities are likely to exist in parental caregiving situations in different settings. The situation as portrayed in the US, where most studies have been done, is likely to provide only partially relevant insights into the situation elsewhere, especially for settings in the developing world.

This study provides a qualitative analysis of the circumstances and consequences of parental caregiving in Thailand. The analysis is based on 20 open-ended interviews, mainly with parents of an adult son or daughter who died of AIDS within the prior few years (but including one case of grandparents who cared for a grandchild who died of AIDS and several cases where a son- or daughter-in-law was given care). A detailed description of the data and methods used for this study is provided in detail in Annex A, together with an explanation of the reference codes used

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to identify each specific interview. The interview guidelines are provided in Annex B. Also, as described in Annex A, comparisons are made with quantitative results based on The Thai AIDS Cases Study (TACS), which is based on reports by key informants covering approximately 1000 cases of individuals living with or dying of AIDS. This means that the findings of this study can be placed in the context of the broader population of parents who lose a son or daughter to AIDS.

## II. Context and setting

Recent estimates indicate that, at the start of 2000, nearly 700 000 Thais were living with HIV/AIDS and nearly 300 000 had died of the disease (The Thai Working Group on HIV/AIDS Projection). HIV prevalence among adults was slightly over 2%. Although this is well below the double-digit levels found in the worst hit African countries, Thailand is second only to Cambodia in terms of prevalence within Asia (UNAIDS 2000a). While incidence has fallen in response to organized efforts to combat the epidemic (Phoolcharoen et al. 1998; UNAIDS 1998), deaths are unlikely to substantially abate for some years to come (United Nations 1999). In common with most moderate- and high-prevalence countries, heterosexual intercourse has been the overwhelming route of HIV transmission in Thailand (UNAIDS and WHO 2000). In the earlier stages of the epidemic, much of the impetus came from commercial sex patronage, but infected men are increasingly spreading the virus to their wives and non-commercial partners. Recent estimates indicate that half of new infections are attributable to transmission between husband and wife (The Thai Working Group on HIV/AIDS Projection). Almost 30% of reported cases had tuberculosis, while pneumocystis carinii pneumonia and cryptococcal meningitis each occurred in about 20% of patients (Chariyalertsak et al. 2001).

Exchanges of services and material support between parents and their adult offspring are pervasive in Thailand, as they are in much of the developing world. The greater economic interdependence between generations, especially elderly parents' dependence on the support of their adult children,

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conditions the consequences for parents of the loss of an adult child through AIDS or other illnesses (Knodel, Chayovan et al. 2000; World Bank 1994). For example, filial obligations in Thailand are supported by widespread norms, including expectations of old-age support in the form of remittances and co-residence with an adult son or daughter (Knodel, Saengtienchai and Sittitrai 1995). One result of this familial system of intergenerational support is that substantial proportions of adult offspring live with or close to parents, regardless of their own health status.

According to the 1995 national Survey of the Welfare of the Elderly in Thailand, approximately half of the adults with a parent aged 50 or over lived with or in the same local community as their parents, half of whom lived with *their* parents. Moreover, the vast majority of adult offspring who lived outside the parental community maintained contact with their parents; almost 90% returned to visit their parents during the previous year and two-thirds of these visited several times (statistics based on original tabulations by the authors).

Thailand also has a relatively well-developed public health system for a developing country—a circumstance that facilitates access to formal health services. In recent years, affordable health insurance has been made available through various government schemes, including a voluntary prepaid health insurance card system that entitles up to five members of a household to almost unlimited access to government health services through a referral system. Many individuals with AIDS take advantage of this scheme (Knodel, Saengtienchai et al. 2000). In addition, persons who are especially poor can receive a 'low-income card' that entitles them to the same services as the prepaid health card but is provided free. However, at least through mid-2001, expen-



sive antiretroviral therapy (ART), which has effectively extended the lives of HIV-infected persons in the more developed countries, has not been available through the Thai public health system, except as part of limited clinical trials (World Bank 2000). Both the health insurance options and coverage of ART may change in the future.

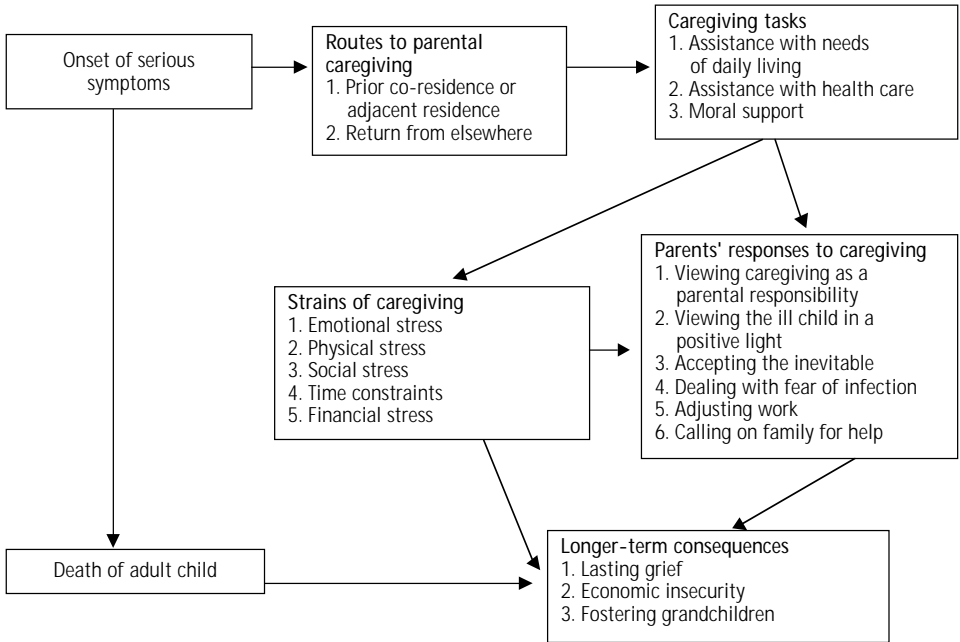
Contrasts in the nature and context of the epidemic in the United States and in developing countries, such as Thailand, including differences in the predominant modes of transmission, underlie the contrasting levels of parental involvement between these settings (Knodel et al. 2001). Sex between men and intravenous drug use are both stigmatized activities among substantial segments of the American population. This could inhibit both gay men and drug users from turning to a parent for assistance when ill with AIDS, especially if the parent has not accepted their son's or daughter's life style. Also, considerable mobilization within the gay community to deal with the epidemic reduces the need to seek outside assistance. In contrast, in developing countries with substantial epidemics, HIV is transmitted primarily through activities that are more widely acceptable in their societies—namely patronage of various forms of commercial or transactional sex by men, and marital intercourse by women. In Thailand, even commercial sex work among women is not strongly stigmatized (Peracca, Knodel and Saengtienchai 1998). Other circumstances are also likely to play a part. For example, far less public assistance to those with AIDS is available in developing countries than in the US and, thus, even greater reliance on informal care is necessary. Moreover, as already noted, in comparison to the US, intergenerational support arrangements in Thailand, as in the developing world in general, more often involve adults co-residing with, or living adjacent to, their parents, regardless of the AIDS situation.

### III. Conceptual framework

Figure 1 shows the conceptual framework that organizes our analysis. Since we are interested in parental caregiving to adult sons/daughters with AIDS, we start with the onset of serious symptoms rather than with HIV infection. It is possible that, upon learning that they are HIV-positive, some individuals, who are still asymptomatic, will seek guidance and moral support from their parents and thus start receiving a form of emotional care even before they become ill. However, in most cases in Thailand, and probably elsewhere, learning of one's HIV-positive status typically occurs only after the appearance of sufficient symptoms prompts the infected person to be tested. Indeed, some may become ill and die from AIDS without ever being tested. Some may strongly suspect that they have AIDS but others may deny it to the end. Whether or not the infected person is tested or recognizes that he or she has AIDS, most needs for care arise at the point when symptoms become serious enough to interfere with daily functioning.

There are two basic routes through which most adult offspring come to be cared for by their parents. Either they are already co-resident with, or living near, their parents at the onset of serious symptoms, or they return to their parental home from elsewhere after they become ill. Once caregiving starts, the caregiver typically performs three major tasks: assisting with the needs of daily living, helping with health care, and providing moral support. Performing these tasks can be challenging for the caregiver on a number of fronts.

**Figure 1. Conceptual framework for analysis of parental caregiving to adult children with AIDS**



Caregiving can lead to stresses that are emotional, physical, social or financial in nature, as well as being very demanding on the caregivers' time. The combination of these tasks and the stress they generate lead, in turn, to a variety of responses by the parental caregiver. In our study, we explore several responses: viewing caregiving as a parental responsibility; viewing the ill son or daughter in a positive light; accepting the inevitable outcomes of the illness; dealing with the fear of infection as a result of caregiving; adjusting economic activities or other work in accordance with the time demanded by caretaking; and calling on family members for help.

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The stresses mentioned above are experienced during the period of caregiving itself. These stresses and the responses to them, as well as the eventual death of the adult son or daughter, can all have longer-term consequences. This study focuses on three sets of such potential consequences. The first is lasting grief over the suffering and death of the child. The second is economic insecurity that can stem from costs associated with caregiving and support of the adult child during the period of illness, as well as the loss of support that the adult son or daughter had been providing to the parents or would have provided in the future. The last set of longer-term consequences involves fostering any orphaned grandchildren left behind when the adult son or daughter dies.

## IV. Results

We start our presentation of the findings by describing the various routes that led to parental caregiving. We then turn to the nature and circumstances of caregiving, the stresses associated with caregiving, and the parents' responses to these stresses. Finally, we consider the potential longer-term consequences of caregiving for the parents.

### A. The routes to parental caregiving

One basic distinction between the various paths leading to parental caregiving is whether or not the adult son or daughter was already living with or close to their parents before becoming ill, or simply returned home following the onset and progression of symptoms. According to the TACS, 37% of adults who had died of AIDS had returned to their place of origin after becoming ill and, among those with living parents, the large majority (close to 90%) either moved in with, or lived adjacent to, them. About a third of those who returned lived only a few months or less, suggesting that many were in quite advanced stages of AIDS at the time of return (Knodel et al. 2001 and original tabulations).

Based on our open-ended interviews, Table 1 summarizes the living arrangements of those who died of AIDS, and their residential moves in relation to their parents. The table covers three periods defined by the illness: the period immediately prior to the emergence of any substantial symptoms;

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the early stages of illness when self-care (and work) was still possible; and the final stage of serious illness when considerable caregiving was needed (and working became difficult or impossible). The two basic paths to parental caregiving, prior to co-residence (or living nearby), versus return from elsewhere, are clearly evident in our qualitative study but, at the same time, the details of the cases reveal that there is much underlying variation within each route. Several cases are quite straightforward, conforming neatly to the basic dichotomy, but most reveal varying degrees of complexity.

In over half of the cases studied, an adult son or daughter co-resided with parents or lived nearby before any symptoms presented themselves. In several cases, co-residence with parents has existed since childhood. In others, the adult son or daughter had more of a come-and-go arrangement, periodically spending time away from home, often in connection with work (e.g. as a fisherman or as a member of a travelling troupe of entertainers). Co-residence sometimes included a spouse. In the rest, the adult child was living and working elsewhere when symptoms first emerged. In one of these cases, the parent moved in with the ill son/daughter but, in all the others, the son/daughter returned ill to the parental home to be cared for by the parents. In some cases, a spouse accompanied the ill son/daughter and joined the parents in caregiving but did not necessarily remain until the end. More complicated series of moves before the son/daughter finally died, however, are not unusual and even include cases where the son/daughter was initially co-resident and then went away, only to return later.

Most caregiving provided by older persons to an adult with AIDS involves their own sons and daughters, and normally ends when the child dies. In some cases, repeated caregiving occurs if multiple family members are infected (e.g. an adult

**Table 1. Living arrangements and moves of adult children relative to their parents, leading to parental caregiving**

Prior to becoming ill	When ill but able to manage on their own	After becoming seriously ill	Sex and marital status of focal child and number of cases	ID
Co-resident with parent(s)	no change	no change	married daughter - 1 single son - 1	C2 R4
	no change	no change	married son - 1	C5
Co-resident with parents and spouse	moved with spouse to spouse's parents	returned to parents with spouse	married son - 1	C4
	no change	remained with parents all the time	single son - 2 married son - 1 divorced son - 1	P3 R5 R7 B2
Nearby with spouse	moved with spouse to parent	no change	married son - 1	R6
	no change	moved with spouse to parents	married son - 1	R1
	left parents and spouse to live elsewhere with new spouse	moved to parents with new spouse	married son - 1	C3
	no change	parent moved in	married daughter - 1	R2
In same locality	no change	moved to parents	single son - 1	B3
	divided time between separated parents	remained with mother	single son - 1	B1
In different locality but spouse co-resides with the parents	returned to parents and spouse	no change	married son - 1	P1
In different locality with spouse	moved to parents with spouse	remains with parent but spouse leaves	married son - 1	R3
	moved to parents with spouse and then moved to spouse's parents	returned to parent with spouse	married son - 1	C1
	no change (but nearby mother-in-law provided care)	moved to parents without spouse	married son - 1	C6
In different locality	no change	moved to parents	single son - 1	P2

Note: This table excludes the case of the grandparents who cared for their young grandchild and thus refers to only 19 cases in total. In addition, in the case in which the mother-in-law, who provided much of the caregiving, was the respondent, living arrangements and moves are stated in relation to the parents, to conform with the other cases, in which the respondent and the parent are always the same.

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son/daughter, his or her spouse, and their young children). Under such circumstances, caregiving resumes after the first family member with AIDS dies and other HIV+ members become seriously ill. In our sample of 20 cases, we encountered five in which the older person being interviewed either provided care for more than one infected individual or was likely to do so (given that a currently asymptomatic but infected adult son/daughter would almost certainly become symptomatic in the future).

These varying degrees of complexity in the routes to parental caregiving arise from a host of sources including the nature of the infected individual's relationship with his or her spouse, prior unstable or alternating living arrangements, and occupational requirements linking work to residence away from the parents. To provide a better sense of the range of complexity encountered in the paths to parental caregiving among our sample, we provide some illustrative examples.



### Case 1. A co-resident single son [R4]

Mrs Nit is a 67-year-old widow and former saleswoman who lives alone in Rayong city on the eastern seaboard. Her son, Pong, died of AIDS at the age of 31, about a year-and-a-half prior to the interview. He was single and had been living with his mother long before becoming ill. He worked at a local gas station owned by relatives. Because Nit is reasonably well off, she made considerable efforts to get treatment for Pong after he became ill. When Pong developed eye problems, Nit brought him for treatment to Chiang Mai, almost 1000km away, where he stayed for two months with relatives. On returning to Rayong, Pong was still able to work. When his condition worsened, however, he remained at home. With the assistance of another son, Nit cared for Pong until he eventually died.

### Case 2. A co-resident married son [C5]

Mrs Lek, a 60-year-old retired day labourer, lives with her 61-year-old husband and two married daughters and their families in a village within an hour's drive from Chiang Mai City. Her only son, Korn, a construction worker, died of AIDS at the age of 26, more than a year prior to the interview. Korn always lived with his parents. Three years before becoming ill, Korn married Dam, another construction worker, who was a widow with two children. Dam and her children moved in with Korn at his parents' home. Korn was the main earner in the family. After becoming ill, he stayed at home where his wife and mother shared caregiving. He was hospitalized several times for a total of several months. After Korn died, Dam moved back to her home village with her children, where she presented symptoms of AIDS. Lek blames Dam for Korn's illness and their relationship is strained.

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### Case 3. A single son who returned home [P2]

Mrs Phet, a 54-year-old self-employed saleswoman, and her 59-year-old husband, a school janitor, live alone in a coastal community in Phetchaburi province about two hours southwest of Bangkok. Their son, Rak, died of AIDS at the age of 27, two years prior to the interview. Rak was single and worked in a glass factory in Bangkok. He visited home often. Phet and her husband became concerned when they observed Rak's symptoms, and brought him to get tested for HIV. Despite being ill and testing positive, Rak continued to work in Bangkok. When Rak's symptoms worsened, however, Phet and her husband insisted he come back home to stay. As an incentive to return, they bought a pick-up truck for him so he could do freelance work locally. Soon after returning, Rak became too ill to work at all. Phet cared for him full time for several months before he died. Her husband continued to go out to work to support the family, and assisted little with the personal caregiving.

### Case 4. An intermittently co-resident divorced son [B2]

Mr Wong, a 60-year-old retired government worker, lives with his wife in a suburban area north of Bangkok. Their only son, Winai, died of AIDS at the age of 30 about a year prior to the interview. Winai had a longstanding history of addictive stealing, gambling and drug use. Wong and his wife made considerable efforts to get Winai to change his behaviour but with minimal success. After Winai spent time in prison, Wong pressured him to join the monastery for several years, hoping that religious life would calm him down. About four years before his death, with financial

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support from his parents, Winai got married and lived with his wife elsewhere in Bangkok. After a few months, the marriage broke up and Winai moved back in with his parents. He reverted to his former bad habits, putting considerable strain on his relationship with his parents. Winai periodically disappeared from home until HIV symptoms appeared, leading to a more stable co-residence. He was ill for over a year, including a final month when he was almost completely immobilized. Before realizing that his son had AIDS, Wong became concerned because Winai was suffering from persistent headaches. He took Winai to a hospital where he was diagnosed as having cryptococcal meningitis. Although the doctor did not tell Wong that Winai had AIDS, Wong soon realized that this was the case.

Wong initially gave his son money to cover treatments. He found out, however, that sometimes Winai was deceptive and used the money for other purposes. He said he stopped paying for treatment because Winai would die anyway and the money was needed to ensure the future for himself and his wife. Both parents provided care for Winai in the terminal stage of his illness. Towards the end, the son was in agony and eventually went into a comatose state. Wong brought his son to the hospital where he left him to die. Wong expressed relief at his son's death, both because it ended the son's suffering and because it meant a reprieve from the financial strains that the illness entailed.

#### Case 5. A remarried son, a daughter-in-law, and multiple moves [C3]

Mrs Mon, a 65-year-old day labourer, lives with her 67-year-old husband, who is in ill-health, and their adult

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single daughter in a village that is within commuting distance of Chiang Mai City. They had five grown children before one son, Sorn, died of AIDS at the age of 37, four months prior to the interview. Sorn worked as a construction worker and local bus driver in Chiang Mai City. His first wife, Daeng, died of AIDS at the age of 30, a few months before Sorn died. Sorn had married Daeng about 7 or 8 years before and originally lived very near his parents. After several years, Sorn left Daeng who, to support herself, became a commercial sex worker at a restaurant in the vicinity. Sorn reunited with Daeng about a year later. She continued her commercial sex work, with Sorn's consent. The family viewed Daeng's work as an economic matter (with little or no moral connotation). She paid rent for a minibus that Sorn drove and provided funds to build a house next to his parents. For a time, she was the main income earner for the family.

Daeng showed symptoms of AIDS for a year or two and became seriously ill five or six months before her death. At this point, she lost her job as a commercial sex worker, and Sorn, urged by Mon, went to be tested for AIDS. Shortly afterwards, Sorn left Daeng and moved to Chiang Mai City. Mon provided care for Daeng who continued to live next door. Mon explained that she felt obligated to do so because of all the financial support Daeng had been providing. About a month before Daeng's death, as her health worsened, Mon notified Daeng's parents of the situation. The parents came to take Daeng back to their home. They criticized Mon for not telling them earlier. Mon continued to visit Daeng after Daeng returned to her parents' home.

During Daeng's illness, Sorn remained in Chiang Mai City, where he moved in with a hill-tribe woman who left her

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husband and children and, in essence, became his second wife. Sorn did not visit or help care for Daeng, nor did he tell the new wife he had AIDS. However, he soon became ill and the new wife cared for him during most of his illness. Sorn's parents only learned of the new wife when Sorn came back home with her when he was near death. He stayed overnight and then was taken to a hospital where he spent two nights. He came back to his parent's home for another two nights. He tried to return to Chiang Mai City to buy poison to commit suicide but was too weak to drive on his own and was brought back to his parents. The next day, the parents took him to a hospital where he died six days later.

These cases illustrate not only how variable the period of parental caregiving can be but also that the duration is determined by a variety of influences, only one of which is the actual duration of the illness. Living arrangements are fluid and influenced by the progression of illness associated with AIDS, social dynamics among family members, and the search for treatments. Stays with parents are often interspersed with periods in the hospital or temporary moves elsewhere. Prior co-residence can vary in degree, sometimes being more of a come-and-go nature than a stable arrangement. In many cases of initially non-co-resident children, it is the parents who urge the adult son/daughter to come back home, although sometimes he/she is reluctant to do so. Parents motivate their children to get tested when they perceive them to be at risk. This was spontaneously mentioned in about a third of all the interviews. The parents' realization that their son/daughter might be at risk can be prompted by their observation of symptoms. Even when the son/daughter lives elsewhere, parents become aware of these symptoms because they see their offspring

on visits or because the son/daughter complains of symptoms. They may also be alerted if their offspring's spouse exhibits symptoms associated with AIDS.

## B. Gender dimensions

The particular caregiving arrangements that emerge are clearly linked to prevailing norms regarding gender roles and are influenced by the marital status of both the parents and their ill offspring. The predominance of women in personal caregiving (whether the illness is related to AIDS or not), is a common phenomenon observed in most societies. The TACS documented a strong gender dimension to parental caregiving, with mothers being more than twice as likely as fathers to have provided at least some care for their son/daughter with AIDS and more than five times as likely to assume the role of main caretaker. The tendency for personal caregiving to be provided by women is also evident in the illustrative examples given above, as well as in the full set of open-ended interviews. Because fathers are typically older than mothers and because adult men have higher mortality than women in Thailand, an adult with AIDS is more likely to have a living mother than a living father to turn to. Indeed, several of the cases involved widowed women. When both parents were available, however, the most common pattern was for the mother to be the main caregiver and the father to play a less significant or even negligible role.

An example that underscores the greater importance of mothers than fathers in personal caregiving is provided by one of our Bangkok cases in which the father and mother lived separately in different parts of town. The ill single son

spent time at each place although, during the initial stages of illness, he stayed primarily with the father who cooked for him and provided company. However, when the son's condition worsened and extensive personal caregiving was required, the son moved in with his mother, where he remained until his death.

Other evidence of the predominance of women in caregiving is provided by cases where the person with AIDS was married. In five of the seven cases where the ill individual was a married man, the wife either acted as the main caregiver or shared responsibility with the husband's mother or mother-in-law. In contrast, in the two cases involving married women with AIDS (including illustrative case 5, above), the husband did not participate in caregiving. Thus the wives of those with AIDS can significantly lessen the caregiving burden of the husband's parents (typically the mother), but the fathers appear less likely to provide much relief.

It is not true, however, that men were completely out of the caregiving picture. Although, in the TACS, fathers were less likely to be caregivers than were mothers, still almost half (46%) were reported to have helped, at least, and 15% of fathers served as the main caregiver. In the current study, for three cases (including illustrative case 4 above), the father seemed to have shared the caregiving role more or less equally with the mother and, in several other cases, played at least a moderately supportive role. Also, men—typically the father or a brother—provided transportation when the person with AIDS needed to go to hospital, and helped when greater physical strength was needed, such as in lifting or carrying the ill person. Thus, while men may play a minor role in routine care, they can be of critical importance when special tasks are required.

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(My husband helped with cooking. He's a very good cook... When (my son) had to go to the doctor (my husband and the older brother) would help carry him. They always helped.

[59-year-old mother, Rayong, R1:463–473]

When he had to go to hospital, his older brother would drive him... His younger brother helped him a lot. He washed his body and applied talcum powder. He (the sick son) was a big guy. His brother did it so I didn't have to help much.

[67-year-old mother, Rayong, R4:97–99, 169–173.

In part, the lesser involvement of fathers in the caregiving (as illustrative case 3 above suggests) may relate to their position as the main income earner in some of the families (and thus the greater opportunity cost, e.g. loss of income, that would be entailed if they devoted their time to caregiving). In addition, in two cases where the father contributed little (as in case 4 above), he appeared to be too ill to help. In another case, the mother kept the condition of the son, who was a transvestite working in a cabaret show, a secret from the father (a military officer), until close to the very end. She was afraid that the father would have difficulty accepting the fact that his son had AIDS. When he was told, the father paid substantially towards treatment expenses. Finally, since most of our interviewees were older women rather than older men or couples, we may have received a less complete accounting of men's roles than of women's.

### C. Caregiving tasks

Caregiving to an adult son/daughter with AIDS involved a wide variety of tasks, ranging from some that would likely be done even for a



healthy co-resident child, to others that are associated with the extreme debilitation that often accompanies the terminal stages of AIDS-related illnesses. Variation in disease progression and the particular opportunistic infections that the individual develops contribute to diverse experiences among caregiving parents. Likewise, the different routes that lead to parental caregiving, as well as the marital status of the ill son/daughter, help determine the duration, extent and nature of the parents' involvement.

When adult children living elsewhere only return at the terminal stage of their illness, parental caregiving is short, although typically characterized by extremely demanding tasks. Part of this time may be spent at the son/daughter's bedside in a hospital, where some tasks will be shared by hospital staff (see discussion below). In contrast, parents whose son/daughter was already co-residing with them before any symptoms emerged typically spend longer periods providing care and deal with a wider range of illness severity. In such cases, parents may enter their caregiving role before realizing the full extent of what lies ahead. Earlier signs of symptoms, such as headaches, fever, persistent colds and weight loss, may not immediately alert parents to the fact that their role as an AIDS caregiver is about to begin. Nor does the adult child necessarily know what lies ahead. Caregiving may, at first, be of an intermittent nature as the child recovers from one opportunistic infection and then later experiences a recurrence or succumbs to a different one. Parents who are with their son/daughter from the onset of symptoms will also typically have a longer period in which to adjust to the deterioration of their son/daughter's physical and psychological health.

The presence of the ill individual's spouse (especially a wife) can alleviate some or even most of the demands placed on

parents (especially the mother) for personal care. Even when parents are present, the wife often assumes the lead caregiving role. For example, according to the TACS, in 54% of the cases of adults who died of AIDS and lived with, or adjacent to, a parent at the terminal stage, the wife was the main caregiver for married sons and, in another 11% of cases, the wife also helped the parent. In contrast, no husbands in these circumstances were the main caregivers for married women who died and in only 16% of the cases helped the wife's parents, who served as the main caregivers (statistics based on original tabulations by the authors). In addition, for married sons/daughters living away from home, the presence of a spouse could delay the return to the parental home and, in some cases, could result in the son/daughter not returning at all. Even in the latter situation, the mother may temporarily move in with her son/daughter to provide help. However, spouses may also leave before any substantial care is needed or, especially in the case of husbands, as the TACS results indicate, do little to assist the parents in their caregiving role. In unusual circumstances, an older person may take care of the individual's spouse who is also ill, or of a grandchild if they co-reside or live nearby, thus leading to a multiple caregiving role.

### **1) Assistance with needs of daily living**

Although the extent and duration of caregiving varied among our sample, many common features emerged from the interviews. The most frequently reported tasks involved those directed towards meeting the ill son/daughter's needs of daily living. These included preparing food, doing laundry, and assisting the ill person in eating, dressing, bathing, and using the toilet.

In the majority of our cases, the parent prepared food for the son/daughter with AIDS. In some cases, where the individ-

ual in question was already co-resident with the parents, this represented a continuation of the situation prior to the onset of illness. But in others, where the person with AIDS moved in from elsewhere, it meant that additional food needed to be procured and prepared. More significantly, however, most parents modified their normal food preparation in one or two ways. Some tried to structure the son/daughter's diet to consist of foods they perceived were particularly healthy and to avoid foods considered as potentially harmful to the individual's condition. By doing so, they hoped to restore the child's health or at least slow further deterioration. Others tried to please the son/daughter by preparing his/her favourite dishes, providing anything the person wished, or serving dishes that were seen as especially delicious but that normally would be reserved for special occasions because of their cost. This latter approach was motivated both by sympathy for the son/daughter and as a way to keep up the latter's strength. Not infrequently, parents combined the two strategies.

I only cooked pork for him. I didn't allow him to eat buffalo meat, chicken, catfish, yesok (a local fish), and wild animals.

[60-year-old mother, Chiang Mai, C1:275–278]

I was careful (about what he ate). I wouldn't let him eat cold food because he was hot inside. It's like he had a fever all the time. I also didn't let him eat seafood.

[61-year-old mother, Phetchaburi, P3:348–354]

I bought him bird's nest soup when I still had money... I bought him good food because I knew that he would not live for long. I just bought him any food he craved.

[59-year-old mother, Rayong, R1:442–461]

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I saw his body getting skinnier each day. So, I never told him not to eat. I let him eat whatever he liked.

[65-year-old mother, Rayong, R5:223–226]

I let (the two sons who died) eat whatever they wanted... Why should I stop them from eating anything. They can't eat after they are dead.

[60-year-old mother, Rayong, R6:234–239]

Several parents mentioned that eventually their children became too weak to eat on their own and had to be spoon-fed. Many were concerned that their son/daughter was not eating enough, could not keep food down, had frequent diarrhoea and/or was losing weight. Thus they encouraged him/her to eat even if, at the same time, they avoided giving food that they saw as risky for the son/daughter's condition. Milk was most commonly mentioned among the types of food they encouraged, perhaps partly because it could be easily ingested but also because it was seen as providing nourishment. Other easily ingested foods they recommended included rice porridge and soups. Several interviewees said they gave their son/daughter bird's nest (a gelatinous substance gathered from the nests of a special type of bird in Southern Thailand that is popularly believed to have curative value), in one form or another. Because it is expensive, it was likely thought of as a special treat but it might also have been thought of as having particular nutritional or curative properties. Foods that parents most commonly avoided giving were seafood, some types of fish, chicken and buffalo meat. Only rarely was avoidance of alcohol mentioned, perhaps reflecting more a lack of interest in drinking by the seriously ill son/daughter than the parent's belief that it would be harmless.

Doing laundry for the sick person was also mentioned in a number of interviews. As with food preparation, this did not

always represent a new chore. However, at the more advanced stages of illness, it could involve washing sheets and clothing soiled by urine or excrement, adding a new, unpleasant dimension to laundry—one that sometimes caused the parent concern about the possible risk of contagion (see below).

Problems associated with incontinence or assisting the ill son/daughter to the toilet were particularly salient, being mentioned in over half of the interviews. Especially towards the later stages of illness, many of the individuals with AIDS were unable to walk on their own and needed help to get to the bathroom to bathe or relieve themselves. In rural settings, the toilet and bathing facilities are usually outside the house, making access all the more difficult. Commonly, the ill person became too weak to bathe him/herself and the caregiver needed to assist. In the middle of the night, providing assistance in getting to the toilet was particularly inconvenient. Also, in some cases, the available caregivers lacked the physical strength to carry or hold up the person with AIDS. Thus spittoons were provided as bedpans for the patient. Some parents expressed concern about the risks of getting infected themselves from handling the containers the bedridden individual used to relieve him/herself. Nevertheless, as unpleasant and burdensome as these aspects of caregiving could be, most parents accepted it in a matter-of-fact manner.

At first, he still could go to the bathroom, but later he couldn't. He would call me when he peed on himself. I understood that he couldn't control that. Later, I had to buy diapers for him. Then I had to clean his butt.

[51-year-old mother, Bangkok, B3:209–215]

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I had to clean up after he defecated. If he could use a bedpan, he would use it. At his later stage, he couldn't go to the bathroom anymore. He would defecate in bed.

[61-year-old mother, Phetchaburi, P3:248–251]

**Mother:** At first, he could go to the toilet himself, but when he got really sick, he had to use a bedpan.

**Father:** Both of us had to help. We had to drag him... We had to dig a hole near the place where he slept. When he needed to defecate, we dragged him to the hole.

**Mother:** We bought him a bedpan first and dug the hole later. I cleaned his body... If he felt hot, we had to shower him.

[70-year-old mother and 80-year-old father, Rayong, R3:170–174]

## 2) Assistance with health care

Besides help with daily living, parents as caregivers typically also became involved in tasks more directly related to the illness, such as monitoring their son/daughter's state, accompanying the AIDS-inflicted individual to health service sites, staying with them at the hospital, seeking remedies and cures, administering medication at home, providing massages to ease discomfort, and providing psychological support to keep up morale.

In all but one of the 20 cases in our sample, the person with AIDS visited a hospital in connection with AIDS-related illnesses. Most visits were to government-run hospitals. Outside of Bangkok, these included both district- and provincial-level hospitals. In two of the three cases in Bangkok, the person with AIDS was referred to the government hospital specializing in the treatment of AIDS patients. In a few cases, private hospitals or clinics were used. Sometimes several different hospitals were tried in the hope

of improving the chances of finding effective help. Frequently, visits were for check-ups and outpatient care, which, in some cases, occurred on a regularly scheduled basis. Most of the persons with AIDS were also admitted to hospitals as inpatients for varying periods of time, ranging from a single night to stays as long as two months. More often than not, those who spent time as an inpatient did so on multiple occasions.

Visits to, and stays in, health care facilities typically involved family caregivers. Visits to such facilities were often made at the parent's urging and the parent often accompanied the patient. As noted above, others besides the main caregiver—typically fathers and brothers of the ill persons—assisted in providing transport to health facilities and, when necessary, helped in lifting or propping up the person with AIDS when walking. Experiences with the health care system seemed to vary widely. Several interviewees complained about the service provided, indicating that insufficient attention was given to their ill son/daughter. One father mentioned that, on several occasions, he tried to have his son admitted to the AIDS hospital in Bangkok, but his requests were turned down. Refusing admission, however, does not seem to be common, given the fact that it was not reported by others and given the frequency with which hospital stays were mentioned. One mother in Phetchaburi reported that her son was discharged after a couple of days (from a private hospital) because they could not pay the high daily cost. Some parents mentioned that, when the doctors discussed their son/daughter's illness with them (at least initially), they were not told that he/she had AIDS. However, others reported being informed about AIDS and counselled by hospital staff. In two cases in Chiang Mai, parents mentioned that either hospital or local health station staff made home visits.

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At the hospital, the doctor didn't spend much time examining my son. He just asked, "Can you eat; do you feel itchy?" I think the doctor thought that my son wouldn't live very long so he didn't pay much attention.

[51-year-old mother, Bangkok, B3:172–177]

He constantly had a headache and got a flu. We were suspicious when he came here (from Bangkok). We took him to a (private) hospital... We all went together. The doctor said he got parasites that went to the brain but that's the only thing he told us. Actually, he (our son) already had his blood tested and knew (he had AIDS)...

[54-year-old Mother and 59-year-old father, Phetchaburi, P2:58–69]

Health workers from the health centre and hospital come to visit him... After he was so ill that he couldn't get up, we received 5000 Baht in financial support. The money was from the health centre and given to us through the housewives' club.

[60-year-old mother, Chiang Mai, C5:368–381]

In Thailand, it is not unusual during hospital stays for a relative to remain with the patient even overnight. This was explicitly mentioned in four of our interviews. It is likely to have happened in other cases as well, although by no means all. In some circumstances, it was virtually a necessity as the inpatient care provided by the hospital staff was seriously deficient, at least in the eyes of the parents. In other cases, the motivation seems to have been largely that of providing moral support.

I stayed at the hospital. I didn't come home at all. My daughter was scared. When I was about to leave, she would ask me not to go. She would hold my hands. She didn't want me to be out of her sight.

[57-year-old mother, Rayong, R2:437–438]



We went to the (provincial) hospital quite often. It's crowded. Sometimes, there's no bed available... Any available space like near the stairs. He slept there. The hospital allowed one person to closely watch him. When he got a fever, I wiped his body. If he wanted to pee, I had to help him because sometimes he couldn't go to the toilet by himself. (Nurses) came only at the time to give medication... They asked how many times he peed or defecated today. Apart from that, I had to do it. When I went to sleep, I leaned over the bedside.

[51-year-old mother, Rayong, R7:158–172; 344–357]

Thus, while hospital stays could serve as a form of respite for a parental caregiver when the son/daughter has had a particularly serious bout of illness, in some situations it could actually add to the caregiving burden if the parent needed to stay with the patient in the hospital. In such cases, unlike when caregiving takes place at home, the parent is not free to mix caregiving with other activities that normally need to be done around the house or local community. Moreover, the physical setting in the hospital can be quite uncomfortable.

In many cases, impending death was preceded by a serious deterioration of the ill person's health, prompting parents to take him/her to the hospital. This resulted in stays that often ended in death. Thus, although most of our cases represent situations in which a parent or other family member provided care at home during most of the duration of the illness, about half of the deaths occurred in hospitals. There were also cases in which the individual died within a few days or a week of being released. Given a choice, many of the parents would probably have preferred to have their son/daughter die at home. At least one set of parents mentioned explicitly that they avoided putting their son in a hospital for this reason. For many others, however, this was not really an option once they sought help at the hospital.

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The day we took him to the hospital, I am not sure if they took off his oxygen. He was admitted at 8pm and died the next morning.

[51-year-old mother, Phetchaburi, P1:186–187]

(I stayed with him at the hospital) five days and he died. He couldn't hang on. He was so sick that he coughed up blood. That's why he agreed to go to hospital. Before, he wouldn't go, no matter what I said.

[51-year-old mother, Rayong, R7:328–332]

I discussed with my husband that we wanted him to be with us even if he had to die. How could we leave him at [the] hospital? We pitied him. We decided to keep him at home.

[61-year-old mother, Phetchaburi, P3:685–692]

Traditional remedies were commonly used in parallel with modern medicine in the cases studied. Modern treatments involved medication and services received from the governmental health care system, private clinics and hospitals, and over-the-counter medicine from pharmacies. Traditional treatments involved procedures performed by indigenous healers and herbal medicines obtained through them or from herbalists. Some herbal medicines required preparation, such as being dissolved in water or, more commonly, being boiled (with the resulting liquid serving as a tonic). Some food supplements could be ingested directly but others required preparation. Five of our interviewees spontaneously mentioned that they gave massages to their AIDS-afflicted son or daughter. In a sense, this can also be considered a form of traditional treatment in as much as, in Thai culture, massage is considered a key remedy for reducing aches and pain. Massages may also have been considered to have a calming effect and, thus, to be of psychological benefit.

A few parents believed that traditional medicines were ineffective and to be avoided from the start. Others became disillusioned as they perceived the effects to be either temporary or non-existent after trying them. Most parents, however, wanted to expand the potential routes that might help prolong their son/daughter's life or improve his/her condition and thus did not want to limit themselves to just one type of medical approach. Some parents, who used traditional medicine for the ill individual, claimed that it helped reduce some symptoms, such as skin rash and loss of appetite. Some saw the food supplements as a way to give their son/daughter nourishment when he/she could not eat a normal meal. Some became desperate in their search for a remedy, keeping up their hope to the very end, as illustrated by one mother who, just hours before her son died, was arranging to take him with her to a distant province to try yet another traditional alleged cure.

Before he became very ill, I went to places that people told me there were good medicines. I went to buy pot medicines (meaning to [be] boiled in a pot) in Suphanburi and Rayong. I've been everywhere. Don't tell me that there is a medicine that can cure this disease. I won't believe it... Some people told me that medicine you boil was good. I bought some for 3000 Baht a pot.

[51-year-old mother, Phetchaburi, P1:247–254; 338–339]

We went wherever people told us that there were good medicines. We went all the way to Sakon Nakorn [a distant province]. We got a medicine that we had to make into small pills. We paid 3000 Baht for it... We pounded it for him and he took it all.

[54-year-old mother and 59-year-old father, Phetchaburi, P2:195–208]

There was little association between the treatment approach and parents' financial status, since a whole range of both

types of treatment is available at varying prices. Parents would employ those of each type to the extent they could afford, sometimes borrowing from others or occasionally selling possessions in order to pay for the treatment (see below). Searching for traditional medicine could require considerable effort and involve long-distance travel to places where the rumoured remedy was available. Seeking such medicines was seen by most parents as part of their role as caregivers. Likewise, parents saw preparing and encouraging their son/daughter to take medicine, regardless of the type or source, as part of their responsibilities. Only one parent in Bangkok mentioned AZT as part of her child's treatment. As far as we could tell, none of the individuals with AIDS described by our sample received multiple anti-retroviral drug therapy (ART), reflecting its general lack of availability through public health outlets up to the time of our study, and its high cost, even if it could be obtained through a private outlet. Overall, our interviewees seemed unaware of ART and the fact that it was being successfully used to treat AIDS in the West. Subsequent to our fieldwork, there has been considerable publicity about ART in the mass media in Thailand as a result of international and domestic campaigns to increase accessibility. Thus, awareness has undoubtedly increased since we conducted our interviews.

### **3) Moral support**

Parents reported a wide range of reactions by their son/daughter as a result of them having AIDS. Several mentioned that the infected individual tried to put on a brave face so as not to worry them. Some felt that their son/daughter was able to accept his or her fate rather stoically. Others were very depressed or distraught, and one tried to commit suicide. Reactions also varied over the course of the illness. Trying to relieve despair and boost the

morale of a person facing a fatal disease is an important but particularly challenging part of caregiving, especially when the illness is severely debilitating and sometimes stigmatized, as with AIDS. The task is all the more difficult when the person being cared for is one's own son or daughter.

Parents mentioned several approaches to boosting their ill son/daughter's mental state. These included calming down (*plaub jai*), providing encouragement (*hai kamlang jai*), and pleasing (*ao jai*) the ill individual. Parents tried calming him/her down when he/she felt desperate about being sick with AIDS; parents encouraged him/her to eat, to take medicine and/or to get treatment in an attempt to counter despair. Another common idea for psychological support among parents who realized that their ill son/daughter would inevitably die was to please him/her as much as they could, especially by providing the best food or the person's favourite food (see above). Such support may help routine care go more smoothly by facilitating cooperation with caregivers.

I told (my son) not to be afraid. Everyone can be sick. I told him to admit it. This is how I comforted him. I told him once we knew (if he had AIDS) we could make a plan.  
[65-year-old mother, Chiang Mai, C3:231–234]

While he was sick and his medicines ran out, he got very bad headaches. He had body aches and couldn't eat anything. I tried to give him moral support. I told him to think about his baby. I told him to buy medicine so that he could eat and go to work.  
[67-year-old mother, Chiang Mai, C4:302–309]

It's the pain in his joints. I tried to give him a massage, but it didn't work. I did it just to give him moral support.  
[59-year-old mother, Rayong, R1:129–132.]

## D. The stresses of caregiving

Providing care to a terminally ill and physically weak patient can result in multiple forms of psychological, physical and social stress for a family caregiver. This is all the more so when the patient is one's grown-up son/daughter and the illness is socially stigmatized, as is often the case with AIDS. Providing care to a physically and mentally weakened person can be very time-consuming, leaving little freedom for the caregiver to pursue other activities, including those of economic or social importance. Financial demands created by the situation can be an additional source of stress if the family is poor and caregiving interferes with their making a livelihood, or if the costs of treatment and funeral expenses exceed their income and eat into their savings.

### 1) Emotional stress

There is probably no stronger emotional bond than that between parents and children. Recent research in Thailand highlights the importance of children as a main element of older parents' psychological well-being (Ingersoll-Dayton et al. forthcoming). A major source of happiness for older Thais is that of seeing their adult children lead a good life, make a decent livelihood, and raise their own families. Realizing that an adult son or daughter with AIDS has a debilitating and fatal illness, observing the progressive decline in the individual's physical and mental condition, and witnessing the suffering that accompanies it, is emotionally wrenching for a parent (Peabody 1986). In addition, as discussed in the section on social strain, below, because of the stigma associated with the disease and the fear of negative reactions from neighbours and acquaintances in the community, parents often hesitate

to share their feelings or seek emotional support from their normal social network (Dane 1991). Thus, it is not surprising that psychological and emotional strain was commonly mentioned as an unavoidable aspect of parental caregiving.

During caregiving, parents encountered various circumstances that could cause emotional strain: facing the worsening condition of their child and the inevitability of death; adjusting their life to accommodate the caregiving role; and trying to do their best to provide care and alleviate their child's suffering. As the illness progresses, parents are forced to witness the deterioration of the ill son/daughter, which is often particularly severe towards the end. It was always emotionally stressful for parents to go through the terminal stage, particularly when they saw their ill son/daughter suffer in pain or have difficulty moving his/her deteriorated body, and knowing that it would end in death.

He hadn't eaten for five days before he died. I wanted him to eat. Sometimes, he didn't eat all day... He asked me to spoon-feed him. Four or five days before he died, his tongue was coated by white film. It's like his tongue was coated with plaster. I felt so sorry for him. I didn't know why this happened to him... He couldn't take it anymore. He asked if I knew that he was about to die... I looked at him and cried... (The day he died) he had a seizure... I called his name but he didn't answer. He was so skinny that his eyes didn't close.

[51-year-old mother, Bangkok, B3:254–292]

I don't want to see anyone have this disease. I nursed him myself. I knew and saw how he suffered. I pitied him but I didn't know how to help him. His sister told me that if there was a shot that could cure him, she would pay for it even if it cost 100 000 Baht... This disease tortures your heart.

[61-year-old mother, Phetchaburi, P3:201–207; 312–313]

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It was quite hard for me (when caring for my son). But what else could I do? I pitied him. I did it for him without thinking that it was a difficulty. When he was moaning, I felt I would lose my heart. It's hard to get used to it. I really pitied him.

[59-year-old mother, Rayong, R1:118–128]

In my heart I wondered how much more he would be tortured, how long we would have to take care of him in that situation. I pitied him and wondered when his bad karma would be finished. I knew that he would not be back to normal.

[51-year-old grandmother, Rayong, R8:792–798]

In the US, in characterizing the response of middle-aged parents to the terminal illness of an adult child from complications due to AIDS, Dane (1991) observed that grief was most acute at three points: 1) when first learning of the diagnosis; 2) when serious symptoms appear; and 3) at the terminal stage. To some extent, this is also borne out in our interviews. For example, as illustrated by the quotations above, the parents we spoke with leave no doubt as to how acute the grief is in the final stage. However, Thai parents often learn of the AIDS diagnosis only when serious symptoms appear and, thus, the first two experiences coincide. This is partly because some adult children, even when they are aware of the diagnosis themselves at an earlier point, try to conceal it from their parents for as long as possible. This is particularly common if the son/daughter resides outside the parental home when symptoms first appear. But, in other cases, the individual does not know that he/she has AIDS until he or she becomes sufficiently ill that the parents insist he/she sees a doctor, sometimes taking the son/daughter to seek medical help, as already noted. One exception to this is when asymptomatic adult daughters or daughters-in-law are diagnosed as HIV-positive during antenatal check-ups.



(My son) could cope with it (knowing he was HIV+) but he wouldn't tell me. His boss came to tell me. He asked if I knew that he was infected. I was shocked and crying. He wouldn't tell me and still worked (at the cabaret). He wouldn't come home.

[51-year-old mother, Bangkok, B3:93–97]

**Interviewer:** When did you know that he got the disease?

**Mother:** I knew when he almost died. I thought he just had a headache. His headache was so bad that he cried... He told me that he went to the hospital about last December after he got sick in August. The doctor told him that he had AIDS.

[65-year-old mother, Chiang Mai, C3:141–145]

**Interviewer:** How did you know that he might have AIDS?

**Mother:** He was weak. He couldn't eat and had a fever. I took him to a hospital where he stayed for three nights. They tested his blood and then he came back home... I didn't know then... He was strong and I thought he was not sick. Later, he clearly got sores and I wondered and asked what's wrong with him and what the doctor said. He didn't tell me. I knew about it later.

[67-year-old mother, Rayong, R4:30–44]

Dane (1991) also believed that, in the US, when individuals learned that they had AIDS, their response was often initially one of disbelief, followed later by acknowledgment at an intellectual level, prior to acceptance at an emotional level. This does not seem to be commonly the case in Thailand, probably partly because parents typically learn of the diagnosis only after the symptoms are quite obvious. In addition, because the AIDS epidemic has been very widely and openly publicized in the media and health system in Thailand, their understanding of the disease is reasonably good (Phoolcharoen et al. 1998; Im-em et al. 2001).

In at least two interviews, parents said that concerns about the expenses they were incurring during caregiving worried them at that time, resulting in anxiety over difficulties they would face in the future, as a result. In addition, some parents felt unhappy about the negative reactions they perceived from other community members. These are also aspects of emotional stress, although we treat them as part of financial and social stress in this analysis.

Emotional stress could also arise if the person with AIDS assumed an uncooperative attitude towards the care being offered by his/her parents. At times, this evoked feelings of anger or annoyance towards the ill person. Parents wanted the child to be cooperative and to be sympathetic towards the situation the parents found themselves in. Some parental caregivers thus found that they experienced a combination of positive and negative feelings towards their son or daughter in the course of caregiving. Sympathy and pity could give way to occasional feelings of resentment when the ill child became difficult to deal with. One mother admitted that, while she was very sympathetic towards her ill son, at the same time she was angry with him for getting infected. Emotional exhaustion could set in, especially when a parent had to repeat the role as caregiver for another infected son/daughter or other family member who came down with AIDS. Likewise, caregiving stress can be multiplied if there is a co-resident elderly parent who simultaneously needs the attention of the AIDS caregiver, as was true for two of our cases.

## **2) Physical stress**

An association between negative physical consequences and caregiving has been shown with some consistency in various studies (LeBlanc, London and Aneshensel 1997).

Physical stress can arise from doing laundry, lifting, supporting or bathing the adult son/daughter, and changing and cleaning the bedding (Brabant 1994). Physical stress could also arise because the parent needed to work harder or longer hours to compensate for the extra expenses incurred as a result of caregiving. While working longer hours was much less common than stopping work to make time for caregiving, it was mentioned in several interviews.

In almost half of our interviews, some reference was made to becoming tired or exhausted, losing weight, or having problems sleeping as a result of care giving. In the case of the couple who were taking care of the young grandchild who died of AIDS, carrying the child a lot because he did not want to lie alone was very tiring for them. In another case, a woman who cared for several individuals with AIDS reported that she had only just recovered from weakness that she attributed to the caregiving. The relentless and time-consuming nature of caregiving during the terminal stage, combined with a lack of sleep, physically exhausted many caregivers.

At the beginning, he still could walk. Later, when he nearly died, he could no longer walk... I needed to support him to get up and eat... It's like he did things a lot slower... That's why I had to spoon-feed him and shower him. I did everything for him... I helped support him to the bathroom... I didn't go anywhere that was far from him. I was skinny then because I didn't have enough sleep. He didn't sleep much either because he was worried. When my son didn't sleep, I stayed up too because I had to look after him.

[61-year-old mother, Phetchaburi, P3:162–177; 269–275]

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When he was really sick, our children came back to be with us because we were getting very exhausted. They had to help out because we needed to get some sleep. It was about ten days that we needed our children to help us out because our son was big and we couldn't lift him alone.

[70-year-old mother and 80-year-old father, Rayong, R3:395–403]

It was awful for me. I looked after them until I was weak myself. [...] I've just recovered. Before, my mother and I couldn't go to sleep.

[60-year-old mother, Rayong, R6:154–157]

While exhaustion was common, many older parents appear to have been able to avoid severe physical stress by calling on younger or stronger family members for the most demanding physical tasks. Also, in some cases, the ill person retained sufficient strength to move on his or her own and even to function almost normally until close to the end. Thus, while physical stress could and did occur for some older parental caregivers, it was not universal. When it did occur, it was typically for fairly abbreviated periods concentrated during the final stages of the individual's illness and did not generally appear to have long-lasting effects.

### 3) Social stress

Being the parent of an adult child who has AIDS, and especially one who takes on the role of caregiver, can lead to stress in interpersonal relationships both within the local community and within the family. As has been widely reported in many different settings, including Thailand, individuals with AIDS (and sometimes other family members) sometimes experience negative reactions from other members of their community (Leary and Schreindorfer 1998; Malcolm et al. 1998; Singhanetra-Renard,

Chongsatitnum and Wibulswadi 1996; UNAIDS 2000b). Much of the social stress experienced by parents is associated with encountering or fearing the stigmatization sometimes associated with AIDS. However, other sources not directly related to stigma can also create social stress on parents in relation to their son/daughter's illness and death. These include exacerbation of pre-existing conflicts within the family or community; the lack of cooperation in sharing caregiving or related expenses; attribution of blame for the infection to the son/daughter's spouse; and disagreements over who should take responsibility for fostering the surviving grandchildren (see section on fostering grandchildren below).

Our interviews included reports of both positive and negative reactions from others in the community. Positive reactions can provide important social support for parents during caregiving, whereas negative ones can add to their stress. Negative reactions were reported in just under half of our interviews, and positive reactions in just over half. In some cases, parents reported experiencing a mix of positive and negative reactions. In a few cases, they reported that their relationships with others in the community remained normal and that no one treated them unusually as a result of their son/daughter having AIDS. The most common positive reactions included visits by others and continuing shows of friendship; the most common negative reactions included gossiping, avoiding contact, acting repelled by the appearance of the person with AIDS, and boycotting food products sold by the family.

As mentioned above, our sample is selective in that it included only those parents willing to be interviewed and who admitted that AIDS caused their child's death (questions about community reaction were omitted in the two

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interviews in which the parents did not admit that their child had AIDS). Thus our sample of parental caregivers may not reflect the full extent of negative community reaction and may over-emphasize the positive reaction. However, it is useful to compare our results with those of the TACS, since the information in that study was obtained by key informants and, hence, not limited to individuals willing to be interviewed. In the opinion of the TACS key informants, most families of persons with AIDS were treated normally by others in the community, and positive reactions were about as frequently mentioned as negative ones (Knodel et al. 2000). The TACS asked about reactions to the family and not specifically to the person with AIDS, so a direct comparison cannot be made. However, our study does not seem to be out of line, at least with respect to reported reactions to family members.

Reactions from community members were most common during the period when severe symptoms were evident. This is not surprising since others in the community, and perhaps even the person with AIDS and his or her family, often did not realize that AIDS was imminent. Even when the family knew earlier, the fact that one's child is HIV-infected could be effectively concealed from others outside the household as long as symptoms were not pronounced. This becomes increasingly difficult, however, once obvious symptoms associated with AIDS appear. Once some members of the community observe these symptoms, the news can spread rapidly. Curiosity and rumour create reactions, both positive and negative.

**Interviewer:** Did your neighbours know or suspect your son had AIDS?

**Mother:** (They knew) when his symptoms appeared... They tried to stay far from us.

**Interviewer:** If your son went over to his friends' houses, would they mind?

**Mother:** No, they didn't say anything. They welcomed him to the house and they ate together.

[60-year-old mother, Chiang Mai, C1:449–473]

**Interviewer:** When did you know that (your daughter-in-law) had AIDS?

**Mother-in-law:** When she got diarrhoea and had sores. Everyone talked about it. When she went out to the market, people saw her. She rode a motorcycle by herself to the market... Later, people started to talk about her and felt repelled by her... Sometimes when she went out and touched something, other people would be afraid to buy it. Sellers in the market asked her not to go there anymore... They were repelled by her but not with me. They still visited me as usual.

[65-year-old mother-in-law, Chiang Mai, C3:422–429; 458–473; 806–807]

Some neighbours were so repelled that they didn't enter our house. They came like they wanted to visit (my daughter) but they stood far away and looked at her through the window. People were afraid.

[57-year-old mother, Rayong, R2:515–520]

Some people thought that they would be infected if they came near my son. Some people in the market wouldn't come near him.

[51-year-old mother, Phetchaburi, P1:580–583]

Negative reaction to their ill son/daughter adds to the strain on parental caregivers who typically are living in the same house, at least by the terminal stage of the disease. Parents

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experienced stress when neighbours or other people in the community gossiped out of curiosity or fear of being infected. Overt negative reactions did not need to be experienced firsthand to cause stress for the parents. Negative reaction directed at the ill individual, a grandchild or elderly parents themselves could be painful even if they only heard about it through other people who maintained normal contact. Other times, parents' anticipation of potential reactions caused them to isolate themselves and their ill adult child from others in the community as a means of avoiding encounters that could be hurtful. This distinction between perceived and actual stigma is a phenomenon associated not just with AIDS, but with other diseases (e.g. epilepsy) that have unfavourable social images (Jacoby 1994; UNAIDS 2000b).

Those who did not hate us came and told us who hated us. How they talked about us. I said forget it... It depends on a person's karma. If we did good deeds, we would get good things in return. If we did bad deeds, we would get bad things in return. They hated us now, but what if it's their turn in the future?

[59-year-old mother, Rayong, R1:359–370]

I told (my son) to look at himself. I didn't feel repelled by him but other people might. He was skinny then. His feet and his arms were so dark. It's like his skin was burnt. I told him not to go out but he said he didn't feel embarrassed. I told him at least to think about me. Other people would say, "How could he go out like this?" I told him not to go out; so he didn't go.

[51-year-old mother, Bangkok, B3:423–433]

Most commonly, negative reactions were directed at those with AIDS but, in some cases, they were extended to their parents, spouse and children. The most common situation in



which co-residing parents experienced overt negative response occurred when their work involved selling food—whether in a home grocery store or as a vendor of prepared foods. Several interviewees reported having fewer customers. This could continue even after the death of the afflicted child. Responses of those who experienced this reaction included quitting or changing their type of work, or going outside the community to sell their food in places where their situation was unknown.

(My daughter who currently has AIDS) goes out with me to sell things. We go to places where people don't know us... She sells broccoli and cabbage. She bags them and rides a motorcycle to sell them somewhere else. She has to go to other places where people didn't know about her. People in this neighbourhood know about her. They would criticize her and, if she goes to a market here, they would gossip about her.

[45-year-old mother, Chiang Mai, C6:845–878]

(I sold) ice and some other things (at this house). Some neighbours told others not to buy from this house; they've got AIDS... At first, I still could sell but my son liked sitting in front of the house. His skin was sort of yellow and dark, so people didn't want to buy from me. So I stopped selling.

[59-year-old mother, Rayong, R1:376–388]

At that time, people didn't understand. They said I got AIDS while taking care of my daughter... Some people didn't even come to my shop... When she just died, I couldn't sell very well... When I joined in at religious ceremonies to help peel fruit, they looked at one another. So, I didn't help peel fruit. When I went to help out at the ceremonies and ate, they would prepare a separate set of food for me. I couldn't join them.

[57-year-old mother, Rayong, R2:231–244; 521–530]

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Negative reactions were by no means universal. Not all those who sold food perceived negative effects. Other parents who did different types of work rarely reported negative reactions directed at them from other people. On the contrary, quite a few parents whom we interviewed mentioned only positive reactions from neighbours and friends who knew the situation. Others felt that their social interactions remained unchanged, with no particular effect resulting from the fact that their son/daughter had AIDS, especially after his/her death.

**Interviewer:** How did people in this neighbourhood feel when they found out that (your son) died of AIDS?

**Mother:** They were the same. They didn't show any disgust. People still bought noodles from his sister. They didn't feel repelled by her [or] by my son. They pitied him.

[60-year-old mother, Chiang Mai, C5:433–447]

(Neighbours) came to visit (my son). I don't know what they had in mind, but they visited him and bought a lot of things for him... They bought food and ate together. Some people came a long way... I don't think (the neighbours changed any) because, when he had to stay at the hospital, a lot of them came over to visit him. I don't know what they were thinking but they came to visit him. There were a lot of people at his funeral.

[54-year-old mother and 59-year-old father, Phetchaburi, P2:358–374]

(My son) got rashes for almost a year. (Our neighbours) acted normally. He liked to sit in front of the house. Our neighbours still came to visit us as usual. He acted normally. He didn't keep himself in. Other people asked how he was. Their children and grandchildren still played with our children as usual.

[67-year-old mother, Chiang Mai, C4:596–611]

One parent viewed her child's death with AIDS as normal, since there were others who died of AIDS in the community and she did not perceive any negative reactions from others. Some parents may not have perceived negative reactions from others because they had little contact outside the household during the time they gave care to their ill child. The lack of social contact could arise either because they were too busy giving care to pursue their social life as before, or because they tried to avoid meeting others out of fear of negative reactions.

Reactions within the family towards the ill adult child are more likely to be positive than are those received from non-family members. However, sometimes individuals in the same household also react negatively. These situations can be particularly vexing or disturbing for the parental caregiver.

I was the only one who took care of her at the hospital... My daughter complained that (her husband) never came to see her. He should visit her. He was very cold... He once came to the hospital but stood far away from her, like he was disgusted. When he dressed at home, he tried to stay far from her. I asked him if he was repelled by her; he said he wasn't. He was just in a hurry to go to work. I asked him, "Don't you see how sick your wife is? You should take days off and take care of her, but you just don't care".

[57-year-old mother, Rayong, R2:165-181]

Most of the negative reactions reported by the parents of those with AIDS, whether directed at the ill person only or extended to other members of the family, were generally due to a fear of possible contagion. Rarely did negative reactions carry a moral overtone. This is consistent with reports of the key informants in the TACS. In this sense, the Thai situation

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may differ from that in other settings where the predominant behaviours associated with contracting the disease are already stigmatized and where religious or moral beliefs may lead some to conclude that having AIDS is the result of immoral behaviour that deserves punishment (UNAIDS 2000b). One implication of this is that effectively counteracting negative reactions may be more feasible in Thailand than where strong moral connotations are associated with the disease. Presumably, it is easier to educate the public about the facts concerning modes of transmission and the negligible risks associated with casual contact than it is to change basic views of what constitutes morally sound behaviour. To be sure, counteracting unfounded fears concerning the risks of casual contact can be a challenge and requires considerable effort. As our recent study of AIDS knowledge has revealed, although basic understanding of AIDS is quite good in Thailand, it is not uncommon for those who have accurately understood the frequent messages about risks of transmission to still harbour some doubts and want to err on the side of caution (Im-em et al. 2001).

As Dane (1991) observed in the US, the sensitive nature of AIDS means that many parents do not disclose the diagnosis to others, thus limiting the amount of social and emotional support to which they can have access. This clearly seems to be the case for many Thai parents whose adult children suffer from AIDS. With only rare exceptions, the parents we spoke to said they either discussed their concerns and problems only with close family members such as their spouse, siblings or other children, or they kept their worries to themselves. Some were explicit that fear of negative reaction was a reason for not being very open to others about the nature of their child's illness.

I wanted to talk to other people, but I was afraid that they would feel disgusted.

[60-year-old mother, Chiang Mai, C5:521–523]

I talked to my other sons and my husband. If I talked to other people, they might make me more miserable. How could you tell other people your sadness?

[59-year-old mother, Rayong, R1:559–563]

I felt worried but I didn't talk to anyone. I just kept it to myself so I felt uncomfortable sometimes. But when I talked to people, they didn't seem concerned. I asked where could I get medicine for my daughter-in-law who had AIDS. They would say I shouldn't mind that much. She would never be cured. She got AIDS by herself so just let her die. Therefore, I didn't really talk to anyone.

[65-year-old mother-in-law, Chiang Mai, C3:846–857]

If I talk to anyone, they would probably say something that would hurt me... I haven't talked to anyone. My brothers and sisters pity me... I don't want to tell them anything because I am afraid that they would worry about me. They have to work just like myself. I don't want to bother them.

[45-year-old mother, Chiang Mai, C6:1124–1144]

I didn't talk to anyone. I don't mind other people's business. I don't like to talk about things.

[51-year-old mother, Phetchaburi, P1: 669–671]

The hesitancy of parental caregivers to share their troubles and concerns with a wider social network was almost universal among those we interviewed. The fact that our sample was selected for persons who were relatively open about the fact their child had AIDS means that, if anything, our results understate this aspect of the experience. Their hesitancy is related both to a fear of negative social reaction and the deeply emotional nature of their feelings of distress.

Some also did not want to burden others with their troubles. Social and emotional stress could be compounded, as a result. The hesitancy to confide in others, especially outside the immediate family, may also reflect cultural values. The need to unburden one's self by openly sharing one's anxieties and problems with others may not be as normatively appropriate as a way to relieve stress among Thais as it is in Western cultures. This is suggested by the last two quotes cited above. Some commentators have noted that non-interference in the affairs of others is a central value among Thais (Mole 1973). Thus, the concept of sharing one's emotional burdens with others may be less pronounced than in some other cultures. This, in turn, may be linked to Theravada Buddhism—the prevailing religion—which stresses the role of the individual in seeking spiritual liberation and generally emphasizes the primacy of individual action and responsibility (Phillips 1967).

#### **4) Time constraints**

As observed by others, AIDS caregivers often find they are no longer in control of their time because demands on them are dictated by the needs of the person with AIDS (Brown and Powell-Cope 1993). This theme arose in many of our interviews. At the terminal stage of illness, when the child's health had severely deteriorated, demands on the caregiver's time and effort could be particularly overwhelming. In most cases in our study, the period requiring such intensive care ranged from less than a month to as long as six months, but most commonly lasted about one or two months.

If we were at home, I wasn't able to do anything, even to cook rice, because he wanted to be with me all the time, either to sit or to lie down with him.

[51-year-old grandmother, Rayong, R8:215–218]

We had to stay all day. We couldn't leave because he would get hungry and sometimes hallucinate. He said, "Who's coming? Why are they all coming?" He was so sick... We had to stay with him all the time... I couldn't work or do anything. I worried about him all the time. When I did something else, I was still thinking of him. I had to come back to see him quickly...

[80-year-old father, Rayong, R3:216–219; 329–330]

Most parents in our study were working before their son/daughter became ill. In many cases, the parents were either self-employed (for example, selling things, running a small shop, or having a small farm or orchard) or hired themselves out as day labourers. Their caregiving role often conflicted with their economic activities. This situation often forced the main caregivers, especially during the later stages of the illness, to choose between taking care of their ill child and going to work.

I couldn't go anywhere. I couldn't do anything else. I had to watch him. In the morning, I had to cook for him and give him the medicines. I had to take care of everything for him.

[61-year-old mother, Phetchaburi, P3:188–192]

We had to watch him all night. [In the] daytime, I let my mother watch him. I was looking after my grandchild. But my mother couldn't handle it. When my grandchild fell asleep, I would help her out. At night, I had to pay attention since he sometimes called me. I also had to stay during the day and couldn't go anywhere else.

[60-year-old mother, Rayong, R6:137–147]

Time demands could be exacerbated when the parental AIDS caregiver was also responsible for providing care to other family members, such as an elderly parent or a young grandchild.

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At that time, I also had to look after my mother. She was sick and slept in the back of the house. My son slept in the house. My mother was over 80 years old. She couldn't take care of herself... In the morning, I would bathe my mother and then go to see my son. But he still could take care of himself then... I would prepare food for him. Then, I went to work. I came back at noon to see both my mother and my son. Before I left, I would prepare his food and medicines and told him not to forget to take them. After I went back to work, I would call to see how he was. After he became very ill, my mother died. My son couldn't take care of himself anymore. I had to do everything for him.

[51-year-old mother, Bangkok, B3:182–203]

### 5) Financial stress

There were numerous ways in which taking on the role of caregiver to an adult son/daughter with AIDS could create financial stress for the parents. As noted in the discussion on social stress, in several cases parents who had small shops or were food vendors lost the business of those in the community who feared the products might be contaminated or did not want to go near the person with AIDS. Also, as noted, caregiving can take significant time away from work and income-generating activities for the person providing care. In addition, if the ill adult child had been contributing to the parents' income, assisting the parents in their economic activities, or providing other services that facilitated the parents' ability to earn income, such assistance is forgone once the child becomes too debilitated to function normally.

Financial stresses can also be generated more directly through the various expenses associated with caring for someone with AIDS. These include food and other costs of daily living, medication, health care fees and hospitalization. Immediately following their child's death, parents are



faced with the costs of the funeral—typically an important and expensive affair in Thailand, as in many other countries (Danziger 1994). Moreover, if the child with AIDS has dependents, the parents may need to take over their support during the debilitating phase of the illness, and often afterwards as well (see section on fostering below).

Increased costs of daily living were mentioned in half of the interviews. One common source of this was buying expensive special foods that would normally not be bought or would otherwise be bought less frequently. As discussed above, these foods were bought to please the AIDS-afflicted person or because they were thought to be particularly beneficial. In other cases, when the ill child moved in from elsewhere, food consumption increased, especially if dependents came along too. In either case, the result was higher expenditure for food.

**Interviewer:** Did you have to pay a lot of money for him?

**Mother:** Yes, about 200 Baht a day, because he wanted to eat different kinds of food... We bought anything he wanted. Sometimes he wanted to eat durian (an expensive fruit) so much... I also bought him Pepsi, Fanta, Sprite. [51-year-old mother, Bangkok, B3:368–374; 537–541]

**Interviewer:** Did you have more expenses while (your son) was sick?

**Mother:** It was his food. His father bought anything (our son) wanted to eat. Sometimes, he wanted to eat expensive fruits... I tried to please him. I knew that he wouldn't be able to live very long... When there were only 2–3 of us, we didn't finish one litre of rice in a day. When he was staying with us, we ate 2 litres of rice plus food and milk powder (for his child). We had to spend from 50 to 100 Baht.

[67-year-old mother, Chiang Mai, C4:385–399; 439–444]

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**Interviewer:** Did you have more expenses during the time he was sick?

**Mother:** Yes. We had to pay for clothes that we had to throw away once he used them. We paid for food like meat, desserts, milk, supplementary food, car rental to the hospital. In total, it was more than 1000 Baht a month.

[60-year-old mother, Chiang Mai, C5:291–299]

Considerable use was made of the health care system for treatment of illnesses suffered by those with AIDS. Doctors' fees, medicine and hospitalizations could be very costly. Some of the better-off parents took their ill child to private hospitals where fees could be very high. Some parents also bought expensive traditional medicines from outside the modern health system. However, medications could also be expensive in government hospitals, either absolutely or relative to the economic status of the family.

I didn't know who to turn to. I worried about the expenses for medicines. It cost 100 Baht a pill at the (government) hospital. I had to pay for painkillers... We had to spend both my son's and my own money together.

[65-year-old father, Bangkok, B1:726–731; 742–744]

We paid more than 100 000 Baht. The (private) hospital was very expensive... We paid a lot of money there. When I think of that hospital, I still get goosebumps.

[54-year-old mother and 59-year-old father, Phetchaburi, P2:247–249]

I had to pay a lot each month... Medicines from the hospital didn't stop the symptoms so he took Chinese and other good kinds of (traditional remedies). I paid several thousand Baht a month.

[67-year-old mother, Rayong, R4:228–240]

In many cases, however, much of the health care expenses were paid for either through government health insurance (especially the voluntary health card plan described above) or through some welfare measure when the family was poor, thus moderating the financial strain imposed on the parents. This is consistent with reports from the TACS (Knodel, Saengtienchai et al. 2000). In at least one case, medicines were purchased from an NGO at subsidized prices.

**Interviewer:** Did you pay a lot of money for his treatment and other things while he was sick?

**Father:** I had to pay at the hospital. He also asked for support as a destitute person... so we paid only half.

[65-year-old father, Bangkok, B1:313–324]

**Interviewer:** What about medicines: did they cost you a lot?

**Mother:** Yes, because I had to buy AZT... I had to pay out of my own pocket... I borrowed money from other people, too... Later, we went to a doctor at Access [an NGO concerned with AIDS]. The medicines there were cheaper. At the hospital it cost me 5000–6000 Baht. I couldn't afford it.

[51-year-old mother, Bangkok, B3:379–396;463–467].

**Interviewer:** Did you pay a lot of money for medical treatments?

**Mother:** Later, I didn't have to pay because I had a health card. If I had to pay for them myself, it would be more than 100 000 Baht.

[51-year-old mother, Rayong, R7:372–378]

Most families who paid large sums for health care out of their own pockets were better off financially and could more or less afford it without suffering great hardship. Many others had some or most of the health care costs covered through government insurance or welfare. None the less, for

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those who were poor, the expenses that were not covered, such as transportation to health care sites and the costs of some medicines, even if they were subsidized, could create financial hardship and put them into debt. In addition, bureaucratic complications prevented one poor family from getting a low-income card that would have entitled the person with AIDS to mostly free health care. As a result, the health care costs they did have, although modest in an absolute sense, created a considerable financial strain for them.

Funerals could involve a particularly large expense for parents. In several cases, including all three in Bangkok, the funeral for the deceased child was deliberately kept modest, with only a few family members attending and formal mourning ceremonies kept to a minimum. The motivations for the modest-scale funerals were usually either financial considerations or the perceived stigmatization associated with the cause of death. In most other cases, however, funerals appear to be of the normal, fairly elaborate type that is common in Thailand, involving considerable expense, ranging from 10 000 to over 100 000 Baht, but typically falling in the 30-50 000 Baht range. The amount parents had to pay themselves, however, was often much less. In five of the six cases in Chiang Mai, and one in Rayong, most expenses were covered by locally organized funeral insurance societies to which the family or person who died had been regularly contributing as a member. Also, those attending the funeral typically made donations, as is customary in Thai society. Contributions also occasionally came from charities. In a few cases, the total collected from various sources actually was greater than the cost of the funeral. But, in others, the parents ended up in some debt.

I asked the Por Tek Tueng [a charity] to arrange the funeral for him... I called them to take my son's body from the hospital to the Temple... We also had to pay for something, such as flowers. We paid a little—less than 500 Baht. Por Tek Tueng also arranged the praying. He was cremated one day after the praying. We couldn't keep a body of a person who died of this disease very long... I didn't tell anybody (about the funeral). I didn't receive money from anyone.

[65-year-old father, Bangkok, B1:387–421]

**Interviewer:** Did you have to spend a lot of money for his funeral?

**Mother:** I joined a village funeral society. I got about 15 000 Baht. Some people helped me. They gave me 100 or 200 Baht, which was a relief. I didn't have to be in debt.

[60-year-old mother, Rayong, R6:387–394]

**Interviewer:** When he died, did anyone help you at his funeral at all?

**Mother:** Yes. Some people gave us 1000 Baht. Some villagers helped out with the ceremony but I also had to borrow money from the agricultural cooperative bank to organize the funeral. I spent all of the loan and the money given by the villagers in merit-making [activities and donations to support Buddhism and thereby gaining credit for the person undertaking them]... At night, I provided good food for the guests... I also gave money to the monks. I paid a lot... But Por Tek Tueng helped with the coffin.

[59-year-old mother, Rayong, R1:294–319]

In perhaps four of our cases, the overall financial strain on the parents associated with caregiving, health care, and the funeral appear to be considerable. In three of these, not only were the parents quite poor to begin with, so that even modest expenses were a considerable burden, but there were also

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at least two people with AIDS involved. In one of these cases, the strain probably would have been eased somewhat if there had not been a bureaucratic problem in granting a low-income card for the daughter-in-law with AIDS.

It was such a mess. I didn't know what to do. I borrowed from this house or that house... Sometimes when I borrowed, they didn't charge interest. They pitied me. I had to dig potatoes to give back their money. There were a lot of expenses. I don't know how much each month. Each day, I had to find them something to eat. I had to be prepared because they had to eat when they were hungry.

[60-year-old mother, Rayong, R6:331-347]

In the majority of cases, however, the financial strain on parents appeared not to be severe and, in several, the strain seems to have been minimal. Some families were sufficiently well off that they could afford the expenses or had non-critical assets they could sell to cover the extra costs. Others had some sources of relief that moderated the amount that the parents had to pay themselves. These included institutionalized sources such as health insurance plans, welfare programmes (including several designated specially for cases of AIDS), local funeral societies, charities and NGOs. In addition, informal sources provided help, such as customary donations towards the cost of funerals from those attending and contributions from other family members. Some of the adult children with AIDS had income or savings of their own that helped cover treatment costs and other expenses. Borrowing to help meet the health care and funeral expenses was also fairly common, but most parents reported that they were able to clear the debt later.

We never had debts before. We did when my son got sick. After he died, we gave back all the money. Our debtors said we didn't have to hurry.

[67-year-old mother, Chiang Mai, C4:507–511]

We didn't have to sell anything but we used up our savings. We are not in trouble but we paid a lot of money.

[54-year-old mother and 59-year-old father, Phetchaburi, P2:340–343]

**Interviewer:** Did you think that the expenses were a burden to your family?

**Mother:** Yes, because there's nothing that we could do but pay. However, his older sisters helped him a lot, too. They chipped in money because they wanted their brother to survive.

[61-year-old mother, Phetchaburi, P3:413–420]

The impression gained from our interviews is that at least some financial strain on parental caregivers was commonly associated with caregiving and the inevitable funerals that followed but, at the same time, only rarely was it devastating. Families pooled resources, took advantage of various formal mechanisms that could help, and parents usually made adjustments in their spending, according to their circumstances. Still, it was more difficult for the poor than for the better off, even though the latter typically spent much more. This impression is consistent with the results of the TACS in which informants reported that the economic situation noticeably worsened for almost a third of poor AIDS parents, a fifth of those of average economic status, and only 7% of those who were better off than average (Knodel, Saengtienchai 2000).

## E. Responses to caregiving

Caregiving to an ill adult child who inevitably faces death in the not-too-distant future is an extremely trying and difficult experience for most parents. In the absence of effective therapies such as ART, the only reasonable hope parents can have during this period is that of prolonging their son/daughter's life somewhat and reducing his/her suffering. As the main caregivers, parents sacrifice significant time and energy for the ill child. Some faced large expenses associated with their child's illness or experienced their own physical problems, including weight loss, body aches and insomnia associated with the caregiving. Most importantly, parents suffered emotional and psychological stress even when the demands on them for caregiving were moderated or minimized by the help of others. Several common responses to these circumstances included accepting caregiving as a natural part of their parental responsibility, seeing their children in a positive light, maintaining hope or accepting the inevitability of loss, seeking help from within the family, dealing with fears of contagion either by denying them or by using precaution in caregiving, and adjusting their time, especially with regard to work and other economic activities. In some cases, these responses served to help parents cope. In others, they were simply the inevitable result of the situation.

### 1) Viewing caregiving as a parental responsibility

Although many parents admitted that the caregiving period was very difficult for them, they usually indicated that they undertook the role willingly. Also, most did not think of the caregiving as a burden but rather as part of their responsi-



bility as parents. They wanted to do their best to help their ill son/daughter.

Well, it's my son. I had to look after him. I didn't think about the troubles. I am his father. I would do anything for my son.

[65-year-old father, Bangkok, B1:432–434]

As a mother, I wanted my son to be cured... I didn't mind how much I had to pay... My son would never be a burden to me. He's my son... It's his life. I've raised him until then.

[51-year-old mother, Phetchaburi, P1:340–343;394–399]

I wondered why I had to be in such trouble but I loved my son. I had to do it. I wouldn't do it for anybody else but this was my son and I pitied him.

[61-year-old mother, Phetchaburi, P3:588–592]

In Thai Buddhist culture, there is a strong implicit sense of an intergenerational contract whereby parents ideally provide the gift of life, care and devotion to their children when the children are young and, in return, the children are obligated to repay their parents with care and material support later in life when old age undermines the parents' ability to function on their own (Knodel, Saengtienchai, and Sittitrai 1995). At the same time, a sense of mutual obligation persists throughout most of the life course, which is expressed in a continual two-way exchange of services and support. Similar cultural prescriptions, typically grounded in other religious precepts, exist throughout much of Asia and perhaps elsewhere (Asis et al. 1995). This system of normatively mandated intergenerational exchanges probably makes it almost unthinkable for many Thai parents to be unwilling to provide a high level of care when their child becomes seriously or fatally ill.

## 2) Viewing the ill child in a positive light

Most parents maintained a generally positive attitude towards their ill child. This reflected the normally close bonds between parents and their children and the fact that most saw the illness as stemming from normal behaviour or at least from behaviour that was tolerable. As noted above, most HIV infection in Thailand is transmitted through heterosexual contact, typically through commercial sex patronage for men and through marital sex with their husbands for women. Unlike drug addiction or homosexual behaviour (both of which are viewed quite negatively by large segments of the population in Western countries), marital sex is viewed as perfectly normal anywhere and patronizing prostitutes, especially for a single man, has been considered quite ordinary behaviour by most Thais (Knodel et al. 1996). The latter may be changing in the wake of the AIDS epidemic, but this is only a recent shift.

It's normal that he would go out (patronize prostitutes) during weekends. I don't blame him for that... I was not ashamed of it. Had my son robbed other people, that's shameful because it meant that I didn't raise him well. But what he did was normal.

[51-year-old mother, Phetchaburi, P1:316–324.]

He was a young man living in Bangkok. He had a lot of friends and also drank liquor. He probably patronized prostitutes when he got drunk. I warned him to use condoms.

[54-year-old mother and 59-year-old father, Phetchaburi, P2:79–84]

Accepting the demands and sacrifices that often accompanied caregiving was probably made easier by the positive view that many parents had of their ill son/daughter. It was common for parents to stress that their son or daughter was of good character and behaved normally before the onset of

illness. Thus, with few exceptions, the parents did not blame the ill son/daughter or consider the fact he/she became infected to be his/her fault. Parents tried to understand what had happened to their ill child, tending to blame bad fortune or other people, such as the son/daughter's spouse. Thus, as the quotes above show, when the ill child was unmarried, or infection was thought to stem from premarital behaviour, parents rationalized the behaviour, saying that it was a normal practice for single men to patronize commercial sex workers or to have affairs with women and it was simply a matter of bad luck that their son became infected. Even in the cases of several married or divorced sons, the parents either implicitly or explicitly indicated that the son's wife had been the source of infection.

(My son) married a widow with two children. He must have got AIDS from his wife. She was older than him.

[60-year-old mother, Chiang Mai, C5:95–97]

He was a *likae* (local type of theatre) actor... He was unlucky that he met those bad women... He's a good person. He was not a delinquent person or someone who went around doing no work. He only worked, played *likae*, and came back home.

[61-year-old mother, Phetchaburi, P3:53–59,514–517]

My son was a good person. He didn't hang out with bad friends. He didn't go out a lot. He always went to temples. He was like this since he was young. He didn't drink either.

[59-year-old mother, Rayong, R1:508–512]

Actually my son had never patronized prostitutes. When he went out, there was no woman accompanying him. He went out with his friends only once (to patronize prostitutes).

[67-year-old mother, Rayong, R4:328–335]

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In only two cases did the parents seem to blame their son/daughter for getting AIDS. One of these was illustrative case 4 in which the son had a long history of problematic behaviour and conflicts with his parents. The father was the only person we interviewed who complained about paying for treatments, arguing that there was no point to it since the son would die anyway. The other case was a mother whose son, a fisherman in Rayong, caught AIDS from habitually frequenting prostitutes. The mother felt he brought AIDS on himself from such behaviour, stating it in a somewhat accusatory manner. Interestingly, hers was the only case we found where the AIDS-afflicted individual was never taken to a hospital. Moreover, she did not play the main role in caregiving but allowed another son to take on this responsibility. She also mentioned that, a week after the son with AIDS succumbed, yet another son died from drug addiction. She denied that the second son had AIDS but mentioned he was losing weight. Her household appears to have been characterized by a number of family problems that may have conditioned her unusual reaction to the situation of having a son ill with AIDS.

In two other interviews, parents also mentioned problematic aspects about their child's character or behaviour, although their attitudes towards caregiving were more positive. In one of these cases, the son was a transvestite whom the mother characterized as lazy and out of touch with his parents for long spells. While she appears to have been a devoted caregiver, she also mentioned that she tried to hide her son's condition from his father (a military officer) for as long as possible because she feared her husband's reaction. In the other case, the parents mentioned that the son physically abused his wife, causing her to eventually desert him and leave the parents to do the caretaking themselves. However, they never expressed any resentment towards the son and

seemed to have devoted themselves fully to his care to the very end.

### 3) Accepting the inevitable

Hope that the ill child would get better helped to keep up some parents' morale during the period of illness and motivated them to do their best in giving care. This hope is reflected in the constant search for treatments to improve their child's health, as reported by a number of parents.

I only wanted my son to be cured. I took best care of him because I wanted him to be cured. I wanted his life more than anything else. I can always find money but I can't take it with me when I die.

[51-year-old mother, Phetchaburi, P1:648–653]

At some point, however, most parents recognized the inevitability of their child's death. This is partly because reasonably accurate knowledge of AIDS has been widespread in Thailand for some time (Im-em et al. 2001; Knodel, Soottipong and Saengtienchai 1997). The government and other organizations mounted an aggressive and sustained campaign to increase public awareness of the epidemic in the early 1990s. Thus, most older people, including the parental caregivers we interviewed, knew that AIDS was incurable and fatal. For some parents, recognition of this probably occurred as soon as they knew and accepted the diagnosis. For others, it may have taken some time to accept this realization. Eventually, most of the parents considered that the death of their child was a forgone conclusion that they could not change. Consistent with Buddhist tenets, some parents viewed the difficulties they faced to be a consequence of their own or their children's karma and, hence, something that could not be avoided.

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I knew that this disease was not curable. I tried to get over it. I expected they [her son and daughter, who both had AIDS] would die eventually.

[68-year-old mother, Chiang Mai, C2:350–357]

I felt sorry for them [her son and daughter-in-law who died of AIDS]. I didn't know what to do. This disease is not curable. I tried to get over it. It must have been because of their karma. They used up their merit.

[65-year-old mother, Chiang Mai, C3:712–716]

The relatively short average life expectancy of those with AIDS makes it difficult for family members to escape the awareness of loss and dying (Brown and Powell-Cope, 1993). Given the recognition that death of their child is inevitable, parental caregivers of adult children with AIDS typically start to experience a sense of grief prior to the actual loss (Dane 1991). Evidence of this process of anticipatory mourning emerged in several of our interviews.

I knew that he was going to die because I saw that from my nephew [who had already died]. He had the same disease... He died before my son did. When I knew that my son had the same disease as my nephew, I started to admit what would come.

[65-year-old father, Bangkok, B1:711–721]

We talked to comfort each other. We talked about how we should adjust ourselves and discussed that our son wouldn't live very long. We knew that he couldn't be cured.

[67-year-old mother, Chiang Mai, C4:647–651]

In one case where the mother only became aware that her daughter had AIDS shortly before the daughter died, there was no time for anticipatory mourning or to adjust to the inevitable. This appears to have made the death even more traumatic.

I wonder why she got sick so quickly—so quickly that I didn't prepare myself. I couldn't cope with it.

[67-year-old mother, Rayong, R2:212–215]

#### 4) Dealing with fear of infection

Fear of AIDS contagion can cause considerable anxiety on the part of caregivers, especially if they are not well informed about the actual risks (Gregory and Longman 1992; UNAIDS 2000a; Chekryn 1989). In Thailand, the extensive campaign to educate the public regarding AIDS has probably reduced this problem. Most, but not all, parents who acted as caregivers in our study were reasonably well informed about their low risks of contracting HIV from the tasks they performed for their ill son/daughter, especially if they took the proper precautions. Over half indicated that they were not afraid of becoming infected through the presence of their child or through caregiving tasks. Many saw caregiving as involving only minimal risk for themselves. Very few seemed to have been truly worried.

I took care of everything. I applied cream to her mouth internally and externally, and cleaned her teeth... Doctors and nurses warned me to wear gloves but I didn't and I was not afraid... I washed her buttocks after she excreted. I did this without gloves... I was not afraid I would be infected. If that's what was going to happen, let it happen. I am old, it's just the time for me to die. I could do anything for her. I wasn't disgusted by her.

[60-year-old mother, Rayong, R2:468–490]

**Interviewer:** Were you afraid because there might be some blood from his wound?

**Mother:** I didn't really think about it. I got over it. I lived this long... I had to be careful. I didn't use my thumb to press the wound. I used tweezers that had to

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be sterilized before putting it into his mouth. I was careful but not afraid or scared.

[51-year-old mother, Phetchaburi, P1:622–629]

Using gloves was frequently mentioned as a recommended practice, especially when dealing with bodily fluids. About half of caregivers mentioned they used gloves at least some of the time. They might skip using gloves when neither they nor the ill child had open wounds or skin problems. In addition, parents did not use gloves for urgent tasks when they did not have enough time to put them on. Several parents intentionally avoided using gloves because they felt it would signify that they had an aversion to their son/daughter and hurt his/her feelings. Some parents were concerned about sharing meals with the ill child. Less frequently, they avoided re-using seriously soiled bed sheets or using the same eating utensils or dishes.

(I was not afraid when I looked after him) I only thought that if I didn't do it, who else would help him? However, I separated his dishes, spoons, forks, glasses, etc. I told him that I didn't feel disgusted... I didn't want to eat his leftovers but I didn't want him to know that I threw them away.

[51-year-old mother, Bangkok, B3:310–318; 375–377]

I wore gloves when I wiped his body and so did his wife. We could be infected if our hands had open wounds. He didn't mind us wearing gloves while taking care of him. (I wasn't afraid), he's my son... (If sheets or clothes were soiled), his wife would burn them and get new ones... I was a little worried about how I should take care of myself while he was coughing.

[67-year-old mother, Chiang Mai, C5:250–271; 499–500]



His father had a wound on his hand so he had to wear gloves. I didn't because my hands were fine except when I had to give him a spittoon... I was never afraid. I never thought of it because he's our son.

[54-year-old mother, Phetchaburi, P2:384–397.]

**Mother:** I wasn't afraid. What had to happen was going to happen. But we were careful. But sometimes we just didn't have time to be prepared.

**Father:** After he died, we burnt all his clothes and belongings. We didn't give them to anyone because we were afraid that they would transmit the disease.

[70-year-old mother and 80-year-old father, Rayong, R3:358–366]

## 5) Adjusting work

As discussed above, parental caregiving typically was very time-consuming, particularly during the final stages of illness. Since many parents were economically active, caregiving could seriously compete with the time required by their work. For some, the financial strain resulting from their child's illness meant that more income was needed. Thus, many parents needed to make adjustments in their working life to accommodate the demands of caregiving. These adjustments ranged from stopping work completely to increasing the time worked in order to earn extra income to meet their extra costs. The type of adjustment depended on a number of considerations including the economic status of the family, the type of work, and who else in the household was contributing to income and caregiving.

One common solution was for the main caregiver simply to stop working during the period when intensive caregiving was required and spend all their time with the ill child. This was made easier if someone else could take over the work or if others in the household were still earning income.

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It's a mother's responsibility. I am a mother. I couldn't do anything else at that time. I didn't work at all. I had to watch him for a full two months. However, his brothers and sisters still worked but I was watching my son.

[61-year-old mother, Phetchaburi, P3:464–470]

Even if (the family business) was very busy, I didn't work at all. I left all the work to my daughter. I chose my son first... I let my daughter run the business.

[51-year-old mother, Phetchaburi, P1:344–346; 450–451]

**Mother:** My husband had to go to work (as a school janitor).

**Father:** But my wife had to stop selling for several months. She had to stop because our son wouldn't eat until his mother got home. He had to wait until his mother got home. So, my wife stopped working.

[54-year-old mother and 59-year-old father, Phetchaburi, P2:406–415]

Disregarding the economic loss resulting from the curtailment of work, reducing work or stopping work altogether is more difficult in cases where the parent is a regular employee in the formal sector than when the parent is self-employed, works as part of a family business, or works as a day labourer hired out on a job-by-job basis. This is clearly evident from the last quote above, which is from illustrative case 3 (presented in the section on routes to caregiving). Gender role considerations aside, it was easier for the mother to temporarily stop her activities as a self-employed vendor to care for their son than for the husband who was regularly employed as a school janitor to take time off from his job. Likewise, in neither of the other cases where a parent had regular outside employment, even when they were also the main caregiver, did they quit their job or completely stop their work. Instead, they attempted to work around it.

**Interviewer:** Did you have to stop your work (as a civil servant)?

**Mother:** No, I came back at lunch. Some days, I couldn't come back. I would call him first. I told him to take care of himself. I would put ice and juices in a place that he could reach.

[51-year-old mother, Bangkok, B3:217–223]

A number of parental caregivers outside the formal sector also did not stop work. Some parents who were quite poor simply could not afford to stop working, even though they took on the main responsibility for caregiving. Instead, they also had to work around the situation. One solution was to enlist the assistance of someone else during the periods when it was necessary to work. Another was to switch the type of work taken on so that more of the income-earning activity could be done at home. Even if the parents were not particularly poor, some types of work, such as agricultural pursuits, might require their attention and, if no one else was available, the parents were left with no choice but to take care of things. In one case, the two parents took turns tending the orchard and minding their ill son/daughter.

After I gave him something to eat, I would go out to earn some income. (I would stop by) to see if he already took the medicines or ate anything. After I stopped by to see him, I would see him again in the evening after I finished selling.

[45-year-old mother-in-law, Chiang Mai, C6:306–317]

I didn't really stop working because I still went out to get a job and did it at home. When I had to go out, I let his older sister take care of him. When I came back, I would take over from her. I watched him as I was working. Sometimes I made desserts for his older sister to sell.

[51-year-old mother, Rayong, R7:466–473]

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**Father:** We took turns. One of us had to stay (at home).

**Mother:** At that time (my husband) didn't stop working. He took turns with me because we still had to take care of the orchard and to spray weedkillers.

[70-year-old mother and 80-year-old father, Rayong, R3:372–387; 484–488]

In a few cases, the time spent working, at least for one parent, actually increased rather than decreased. This was the case for several parents whose economic status was quite poor. The parent needed to meet the additional financial demands created by caregiving or to compensate for the loss of income that the ill son/daughter would otherwise have been contributing to the household.

I had to do more hired work (when he was sick) because my son was the breadwinner before he got ill.

[60-year-old mother, Chiang Mai, C1:416–418]

At that time, my husband was the only breadwinner. I had to take care of my son and my grandchildren. My husband had to work harder. He worked more jobs. Besides driving a three-wheeled taxi, he was a construction worker. He did everything other people hired him to do.

[67-year-old mother, Chiang Mai, C4:493–500]

After (my son) was sick, everyone had to work harder because we had more expenses.

[60-year-old mother, Chiang Mai, C5: 338–340]

Overall, the impressions provided by our open-ended interviews with parental caregivers regarding the impact on work patterns conform to the results of the TACS. Key informants in the TACS were far more likely to report that parents had to stop or reduce work in order to meet the demand of caregiving than to say that parents increased the work they did to help meet expenses (Knodel et al. 2000).

## 6. Calling on family members for help

The practical implications of the substantial physical, emotional, financial and time demands created by AIDS caregiving meant that those who assumed primary responsibility for it could not cope with everything on their own. One common response was to solicit help from others within the family. As the discussion of social stress and community reaction pointed out, the stigmatized nature of AIDS often reinforced the tendency of parental caregivers to limit the call for help to within their own immediate family. However, given the nature of many of the needs involved, the family would, in any case, normally be the source of help sought or offered even if the illness involved had no stigma attached to it.

In the sections on caregiving tasks and the stress of caregiving, considerable references have already been made to family assistance. With respect to caregiving, this ranged from more or less equal sharing of the tasks between both parents or between a mother and a daughter-in-law to occasional help from other family members for specific tasks. Thus, mention was made of assistance that was provided to parental caregivers by their own spouses, the spouses of their ill child, their other adult children, their siblings, their siblings' adult children, and even their own elderly parents. In some cases, the spouse or sibling of the ill person might, in fact, have been the primary caregiver, with the parent playing more of a supportive role. Some assistance provided to older parents in their caregiving was of an occasional and specialized nature, such as help with lifting or moving the ill person or providing transport to a health facility. Except for health workers who provided care during hospital stays, few non-family members seemed to have been involved in caregiving in any substantial sense in the cases we inter-

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viewed. Even during hospital stays, family members sometimes helped parents attend to the ill person. In cases where an unmarried son/daughter lived elsewhere during the initial stages of illness before returning to their parents, non-family members may have played some role in caregiving, but this was not covered in our interviews.

Besides help with the tasks of caregiving, financial assistance was often needed to cover the range of additional expenses associated with a situation in which an adult child became ill with, and died from, AIDS. To varying extents, institutionalized welfare and insurance mechanisms eased the burden. But, for many cases, such assistance was insufficient to fully alleviate the financial strain. With the exception of funeral expenses, for which Thai customs encourage other community members who attend the funeral to make monetary contributions, informal financial assistance was typically sought from, or offered by, other family members. The assistance could be in the form of a loan, especially if it was from someone other than one of the other adult children, or as an outright contribution. There were a few cases in which non-family members, namely former employers of the child with AIDS, helped with some significant aspect of the expenses.

Assistance from other family members (especially their other children), in terms of visiting, keeping parents company, lending or contributing money, or offering transportation, reduced the parents' sense of being alone in their caregiving role. As noted above, during the period of the child's illness, if parents wanted to confide in someone, they would speak to their family members, especially their spouse, other children or other relatives, but generally not to friends or neighbours. By and large, as with caregiving and informal financial assistance, social support for the parents of adult chil-

dren who died from AIDS in Thailand remained a family affair.

The extent to which assistance was forthcoming from other family members varied among those we interviewed. This was partly a reflection of the different degrees of need, as determined by the severity of the symptoms and the economic situation of the parents. However, there also seemed to be important differences in how closely knit or cooperative members of families were. Thus, while seeking family assistance was very important in helping parents cope with the situation, the success of this strategy depended on pre-existing family relations and was not necessarily ensured.

## F. Longer-term consequences

So far, we have focused on the parents' situation during the time spanned by their adult child's illness and funeral and the immediate consequences. We now turn to the consequences experienced after the death and funeral of the son or daughter with AIDS. Since the interviews typically took place within only a year or two of the death, truly long-range consequences still lie in the future and cannot be assessed. Nevertheless, our interviews provide some insights into longer-term consequences. In this section, we focus on lasting grief, economic insecurity and fostering grandchildren. We give particular emphasis to fostering because of the considerable interest generated by the issue of AIDS orphans in discussions of the epidemic generally. We do not include long-term community reaction to parental caregivers as a separate subtopic because it appears to have been minimal. As noted above, most of the

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negative reactions by other community members reflected an avoidance of the person who was ill out of a fear that social contact carried some risk of contagion. Once the person with AIDS died, the basis for the negative reaction typically dissipated. The main exception was the persistent stigma attached to AIDS orphans that was evident in a few cases and that is discussed in connection with the issue of fostering below.

### 1) Lasting grief

Probably the most serious consequence of losing a child to AIDS is the emotional toll that, for many parents, results in sadness and grief that lasts long after the funeral is over. Various studies have found that the death of an adult child may be the most emotionally distressing of any of life's experiences (Aldwin 1990; De Vries, Lana and Falck 1994; Moss, Leshner and Moss 1986-87; Sanders 1989). AIDS as the cause of death may make the experience even worse, given the intense suffering that accompanies the illness, especially



Funeral procession for a young man who died of AIDS, Thailand. Photo: John Knodel



during the terminal stage, and the possible stigma attached to the illness (Gregory and Longman 1992). While grief is difficult to measure and cannot be compared in any direct way to the other consequences, it was clearly profound for many of the parents we interviewed. Even for those who said they had come to terms with the death of their child, expressions of sadness were hard to suppress.

I had to get over it. I tried to think that everyone would die whether it be a good or bad death. But I was very sad when my son died. I cried every day but we all have to die someday. I will die and he will die, too. When I think about it, I am overwhelmed.

[59-year-old mother, Rayong, R1:493–499]

I am still thinking of him every day. I keep looking at his picture.

[54-year-old mother, Phetchaburi, P2:497–499]

I still miss him every day. I cannot forget about him even if it has been two years. When I close my eyes, I can still see myself nursing him every day.

[61-year-old mother, Phetchaburi, P3:628–631]

**Interviewer:** How did you feel after your son died?

**Mother:** I was sad. Children shouldn't die before their parents.

[67-year-old mother, Chiang Mai, C4:635–639]

Accepting the death of an adult child is made all the more difficult because it represents a reversal of the expected order of life events, as the last quote above articulates (Moss, Leshner and Moss 1986–87). That a child should die before a parent can be seen as unnatural, adding to the tragedy. The extent to which parents had come to terms with their loss, at least by the time of our interviews, was difficult to judge. In cases where the parent and child main-

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tained a close emotional relationship, the sense of grief may have been reinforced by the sense of loss of emotional support that the death brought with it.

**Interviewer:** Now that your son is dead, is your life more difficult without him?

**Father:** I don't know who to talk to when I am in trouble. Yes, my life is more difficult but I don't know who to turn to.

[65-year-old father, Bangkok, B1:571–578]

Several people expressed the fact that they had come to terms with their loss, including the case of the adult child and parents who seemed to have had a particularly problematic relationship.

I am sad when I think about the old days. It's sad. However, it's something no one can escape from. It's natural. We have to let go of it. We must think about our future. We still have plans for our future. We can't keep thinking that he shouldn't die. What would come of it?

[60-year-old father, Bangkok, B2:491–497]

### 2) Economic insecurity

As discussed in detail above, most families experienced some financial strain during the period of caregiving and the holding of the funeral, although only exceptionally was the impact severe. Now we turn to the question of whether the death of the child had any lasting financial repercussions for the parents and whether it was likely to lead to sustained or subsequent economic insecurity. The intermediate and longer-term implications of the death for the parents' economic situation depended on a number of influences that differed among the cases we studied. Several that

are likely to be particularly important are the economic status of the parents, the extent to which the parents depended on the deceased child for financial support or assistance with economic activities before he/she became ill, the number of other adult children who could assist the parents financially, and whether or not parents were fostering a grandchild as a result of the death.

Slightly more than half of the parents we interviewed were poor. These parents were clearly more vulnerable than the remainder who were moderately well off. In about half of the cases of economical impoverishment prior to a son/daughter's illness, the unfavourable economic implications of the illness and death of the son/daughter appear to have lasted up to the time of interview and can be anticipated to continue into the indefinite future. Of the seven cases we judged to suffer lasting effects, four were also fostering grandchildren. Among those who were better off to begin with, few, if any, seemed to have suffered lasting economic hardship as a result of losing their child, even when they were fostering a grandchild.

One way that a lasting economic impact could have arisen would have been if the parents needed to sell important assets that were crucial to their livelihood in order to pay for expenses associated with their child's illness. In five cases, parents needed to sell valuables for this purpose but, in most cases, productive assets on which their income depended were not involved. Most commonly, they sold gold jewelry. In only one case did the parents sell some of their land. In another, in order to pay for his treatment, the ill son sold land his mother had given him. Since, for many Thais, gold has traditionally served as a form of savings that could be drawn on when needed, the sale of gold may have cut into their savings. However, given that the gold was not playing

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any crucial part in their current support and was probably intended for emergency situations, such as the illness of their son/daughter, its sale would, at most, have detracted from their sense of future security rather than impacting their current economic well-being.

I can tell you with no shame that I sold all the jewelry I had. I thought it didn't matter. Whatever had to happen would happen anyway. One day I would have them back.

[51-year-old mother, Bangkok, B3:523–528.

Many of the poorer parents had few assets of value that they could sell. However, another avenue that could lead them to a situation of more lasting economic hardship would be to take on serious debt as a result of borrowing to cover the expenses of treatment, caregiving or the funeral. In at least one case, this appeared to have happened.

Interviewer: Did you have to borrow money from someone to cover the expenses due to his illness?

Mother: I got a loan from the Cooperative. Now, I'm still in debt. I have very little income but have to pay the interest. This is my worry.

[59-year-old mother, Rayong, R1:256–260]

Multiple deaths could also compound the impact even if the family had some savings before. In one unusual case where two sons and their wives died of AIDS and a third son was murdered, the economic impact was substantial. Even though the family had earlier sold land for a very substantial amount, the mother was eventually reduced to poverty by the series of misfortunes. Her situation was made worse by the need to foster a grandchild.

My two sons both died here. I took them to see doctors until I didn't have any money left... I have been looking

after (my granddaughter) since she was eight months old. I wanted to give her to her mother's parents but they didn't want her... I told them to take her so that I could make a living... I had to sell everything that I could. I sold a television set, everything to buy medicines and food. I borrowed from everyone. One or two hundred Baht from each household. I was struggling... When my sons all died, I did freelance work like growing pineapples, chopping pineapples. I can't work like that anymore. I will faint.

[60-year-old mother, Rayong, R6:199–202; 288–294; 318–329; 471–475]

The most frequent source of serious and lasting economic consequences, when they occurred, was the loss of the support that the deceased adult child had been providing to the parents. This usually occurred because the child was co-resident and had been the main breadwinner for the household or played a crucial role in their ability to make a livelihood.

While he was alive, his father would schedule shows for him and he would go to play *likae* (local type of theatre). Now that he's gone, we don't take any jobs because we don't know who can be the actor. So, we stopped our *likae* business. *Likae* was our job. Without him, there's no job.

[61-year-old mother, Phetchaburi, P3:498–507]

At that time, I still had some money and savings. He gave some money to me. He earned good income. He went out on fishing trips and gave me 3000–5000 Baht a month. I could save up some of the money. Now, I don't have any savings.

[65-year-old mother, Rayong, R5:41–47]

**Interviewer:** Did you feel that your life was harder after he died?

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**Mother:** Yes. I only have one son. He was our breadwinner.

[60-year-old mother, Chiang Mai, C5:397–400]

Lasting hardship could also arise because the child had been making regular contributions or remittances to the parents. Although a number of the deceased adult children gave monetary gifts to their parents at least occasionally, in only one such case did it seem that the loss of these contributions was crucial for the longer-term economic security of the parents. More commonly, the contributions had mostly token significance and were not crucial to the parents' economic well-being.

(Now) if I don't have money, I have to borrow from other people. Before, I still got some money from my son. Perhaps 300 Baht every 15 days. I could still hope to get some money. Now, I don't know who to depend on. Don't even talk about my daughters. They have never given me money. They usually ask me for that.

[65-year-old father, Bangkok, B1:583–591]

**Interviewer:** Now that he's gone, have you lost some of your income because he gave you some money when he was alive?

**Parent:** Sometimes, but that doesn't cause us any troubles because we still can help ourselves.

[54-year-old mother and 59-year-old father, Phetchaburi, P2:325–331]

(He gave me money) but not a lot. He usually gave me just 300 or 500 Baht at a time, for me to make merit. He didn't give it to me monthly. He had his own family and expenses. I didn't want to bother him. I could find money myself.

[59-year-old mother, Rayong, R1:262–271]

In most cases, the child with AIDS was not playing a crucial role in the economic support of the parents. In perhaps half of the cases, the child neither made monetary contributions nor helped in economic activities. In some cases, particularly among those who were not poor, the parents were more likely to help the child out even before the illness than the reverse.

I never asked (for money) from him. If he didn't have money, he would ask me. It's only he who asked me. He rarely gave money to me.

[51-year-old mother, Rayong, R7:456–460]

To a large extent, the impressions gained from our open-ended interviews are consistent with the finding of the TACS. In that study, the key informants judged that about a fifth of parents who lost an adult child to AIDS suffered serious sustained economic consequences. Also, although poorer parents were reported to have been less likely to have incurred substantial expenses in connection with treatments, they were still considerably more likely to have suffered substantial financial hardship (Knodel et al. 2000). Neither study, however, is able to accurately anticipate what the eventual effect will be on the parents when they reach old age and may need to depend on adult children for their support. In only two cases in our limited sample did the parents have no remaining living children after the child with AIDS died. However, in both of these cases, the parents had, or were entitled to, retirement benefits and appeared to have sufficient financial resources to ensure their future economic security. In the remaining cases, the parents had other living adult children who presumably would fulfill their expected role by providing old-age assistance, if needed. One likely exception was the case of the grandparents who cared for the grandchild who died of AIDS. Their HIV-positive son was

their only child. Although, at the time of interview, he was still healthy and had been for a very long time, if he died of AIDS, the parents would be left childless. The parents were not poor but had already sold some of their land to cover the expenses incurred by being responsible for the grandchild. If their son became ill and they sold most or all of the rest of their land to cover expenses, they could end up in an economically precarious situation in their old age.

### **3) Fostering grandchildren**

One potential long-term consequence of losing a son/daughter to AIDS is that parents may need to foster the grandchildren left behind. This is the one impact of the AIDS epidemic on older persons that has received the most attention in the mass media and in the discourse of international agencies concerned with AIDS (see e.g. UNAIDS 1999; UNICEF 2000). These grandchildren are commonly referred to as 'AIDS orphans' even when one of their parents remains alive. Projections have indicated that the number of minor children in Thailand who will lose their mother to AIDS will approach or even exceed 100 000 by the year 2000 (Boonchalaksi and Guest 1993; Brown and Sittitrai 1995). TACS results suggest that, following the death of the first spouse to succumb to AIDS, the surviving spouse typically takes care of their children. Otherwise, grandparents typically do (Knodel et al. 2000). Even when the children are cared for by the surviving spouse, they may all be living with the grandparents. Moreover, the surviving spouse is often HIV-positive and, thus, will eventually die of AIDS before his/her children reach adulthood. Under these circumstances, one set of grandparents typically takes charge of the orphans.

Among the 19 cases of adults who died of AIDS, on which our interviews focused, nine had children of their own and



**Table 2. Living and fostering arrangements of the minor children of sons/daughters who died of AIDS (limited to cases with children)**

Marital status at time of death of adult who died of AIDS and relationship to person interviewed	Number of minor children of person who died	Living arrangements and moves during the illness of the parent	Living arrangements and moves following death of the parent up to time of interview
Married son-in-law (C6)	1	parents (nearby maternal grandmother)	with mother (who is HIV+) and maternal grandmother who moved in
Married son (P1)	1	with parents and paternal grandparents	first with mother and paternal grandparents; then mother moved out leaving the child with the grandparents
Married son (R1)	1	with parents (nearby paternal grandparents)	back and forth between mother and paternal grandparents; after mother died of AIDS, with paternal grandparents
Married daughter (R2)	2	with parents and later also with maternal grandmother who moved in to help care for her ailing daughter	father moved out, leaving children with maternal grandmother
Married son (C5)	2 step-children	lived with mother and stepfather at stepfather's parents' home since before onset of AIDS	mother and both children moved to be with maternal grandparents; the mother has started to show symptoms of AIDS
Remarried son (C4)	2 (1 with 1st wife; 1 with 2nd wife)	child of 1st marriage lived with paternal grandparents (mother left and remarried); child from 2nd marriage first lived with parents but, after father became ill, parents and child moved in with paternal grandparents	child of their son's 1st marriage went to live with mother; child from 2nd marriage (who appears to have AIDS) lived first with mother and paternal grandparents but mother remarried leaving child with grandparents
Divorced son (B2)	1	with mother and maternal grandparents	with mother and maternal grandparents
Divorced/separated son (twice married) (R3)	2 (with 1st wife)	one child lived with mother and maternal grandparents; other child lived with paternal grandparents and father (who moved to his parents' home when ill with new wife who left before he died)	one child lived with mother and maternal grandparents; other child lived with paternal grandparents
Widowed son (R6)	2	first with parents; after mother died of AIDS, one child went to maternal grandparents and other child went with ailing father to paternal grandparents	one with maternal grandparents; one with paternal grandparents
Separated son (R7)	1	with parents and paternal grandparents (but mother left during father's illness)	with paternal grandparents
Grandchild of widowed HIV+ son (R8)	1 (grand-child)	paternal grandparents	N/A (grandchild died of AIDS)

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one had two step-children. In addition, as noted above, one additional case focused on the grandchild of a HIV-positive widowed son. In total, these cases involved 16 children who lost one or both parents. Our interviews make clear that the routes that lead to grandparents fostering grandchildren can be straightforward or quite complex. Table 2 summarizes the living and fostering arrangements of these children, both during the time of their parent's illness and following the death of the parent. It also summarizes the moves of parents and grandparents that affected the living arrangements during these two periods.

The most striking feature that emerges from Table 2 is that, by the time of our interviews, all but one of the grandchildren (excluding the grandchild who died of AIDS) were living with a grandparent. In five of these cases, a surviving mother was also present and may have helped or taken primary responsibility for the children. However, three of these mothers had already presented AIDS-like symptoms and were likely to die in the near future. In six other cases, either a mother or father survived but had left their children to be raised by the grandparents. Although not evident from the table, in some of these cases other family members in the grandparental household assisted in raising the children. More typically, however, the grandparents themselves took primary responsibility.

The cases we studied suggested that the routes that lead to grandparental fostering of AIDS orphans are closely linked to the routes that lead to parental caregiving to adult children with AIDS. As the main caregivers to the ill adult child who either already co-resided before the onset of illness or who returned to the parental home during the illness, parents of the person who died of AIDS are likely to inherit the responsibility for the ill son/daughter's offspring, particularly if the

ill child's spouse is dead, is also infected, or is not in a good position to take care of children. All but two of the AIDS orphans resided in a grandparental household at the time of the parent's death and all but three of these remained (or ended up back) in those same households afterwards. Two of the three cases where the grandchildren did not remain involved stepchildren who moved with their mother to the maternal grandparental household, and the third case involved a grandchild from a son's first marriage who was sent to live with the mother who had remarried. For the two orphans who were not in grandparental households at the time of the parents' death, both were in households near the grandparents who eventually fostered them. Thus, notwithstanding the exceptions already noted, the future living arrangements of the AIDS orphans in our study seem to have been largely determined by how living arrangements evolved during the course of their parent's illness.

Grandparental fostering may be the result of deliberate planning or it may occur more or less by default through the unfolding of circumstances. They may also involve conflicts between competing sets of grandparents or between grandparents and the surviving parent. Three additional illustrative examples provide a sense of the range of situations that occur.

#### Case 6. Unplanned and reluctant fostering (R1)

Mrs Jaew, a 59-year-old married woman, earns her living as a wage labourer in an orchard near her house in Rayong. She takes care of a six-year-old grandson whose presumed father, one of her sons, died of AIDS three years earlier. The boy's mother died of AIDS two years later at the age of 35. Even though her son was symptomatic and

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died first, Jaew believed that her son was infected by his wife, who at one time had run away with another man but returned pregnant with the little boy. Both because of this and because a doctor once told her that her son was infertile, Jaew doubts that the boy is her son's own child. After Jaew's son died, his wife ran off with another man, leaving the boy with Jaew. Later the mother took the boy to live with her on several occasions but, when she became ill, she again left him with Jaew and did not return. Now that both her son and his wife are dead, Jaew feels she has little choice but to raise the boy, even though she did not want this responsibility. She is poor and feels it puts her under a financial strain. In addition, fostering the child has created other problems. Although Jaew is sympathetic to the boy, and he seems to be very attached to her, other members in Jaew's family show negative feelings towards him. A son of Jaew and his family, who co-reside with her, are afraid of getting infected from the boy, even though the boy has tested negative for HIV. The son and his wife insist that the boy eat separately from their own children and use separate dishes and utensils. Moreover, Jaew has experienced difficulties trying to enroll the boy in kindergarten. One school refused his admission because he was an AIDS orphan. She succeeded in enrolling him in another but feels that the school officials are not pleased about having the boy there.

### Case 7: Unplanned but willing fostering (R2)

Mrs Boonsri, a 57-year-old married woman from a rural area half an hour from Rayong City, was on an extended visit to one of her married daughters in the south when she received an urgent call to come home. Another mar-

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ried daughter who lived in a shop house not far from Boonsri's own home was ill and needed her help. She returned immediately and moved in with her ill daughter to take care of her, mind her two children, and help run the grocery shop. The daughter had rather suddenly become seriously ill with AIDS, and died two weeks later. During the illness, the son-in-law did not help with care-giving and only reluctantly visited his wife once when she was in the hospital. At the time of our interview, almost a year later, Boonsri and her husband lived in her daughter's shop house with the grandchildren, who were 7 and 14 years old and attending school. Boonsri and her husband fully supported the children, paying school expenses, among others. The children's father (Boonsri's son-in-law) moved out after the wife died. According to Boonsri, neither he nor his well-off parents showed any interest in the two children or assisted with their support. Boonsri had not planned to take full responsibility for the grandchildren, although she is willing to do so. She seems to want to do her best to ensure their welfare. Since she and her husband are of moderate economic standing, the extra costs of raising the grandchildren are only a modest financial strain for them so far. Nevertheless, she feels resentful that the father and his parents have disassociated themselves from any responsibility for the children.

#### Case 8. Planned and determined fostering (P1)

Mrs Chom, a 51-year-old married woman, is relatively well off and runs a small family business near the town of Phetchaburi. She is currently raising her six-year-old granddaughter, daughter of her eldest son, Seri, who died of AIDS three years earlier. Chom is very proud of her son

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and the fact that he was a military officer. She is not ashamed that he had AIDS. She attributes it to his occasional patronization of commercial prostitutes, a behaviour she considers normal for men. Chom only learned that her son was married when her granddaughter was born, and believes he was tricked into the marriage by the wife. Right after the birth of their daughter, Seri, his wife and newborn daughter moved in with Chom. Seri's wife immediately resumed work in town, commuting daily and leaving her infant daughter with Chom. Thus, from the very beginning, Chom took care of the granddaughter most of the time. Chom says that, before he died, Seri asked her to take custody of his daughter after his death and said he specified this in his will. He also placed his financial assets in a trust for his daughter. Chom is determined to be the one to raise the grandchild and has tried to minimize the involvement of the grandchild's mother. With Chom's encouragement, Seri's widow moved out to live with her own parents, leaving the daughter with the paternal grandparents. Although the daughter-in-law comes to visit and brings gifts for her daughter, Chom describes her as an irresponsible mother who does not truly love her own daughter. Chom appears to try to discourage the mother's visits and says she is happy to pay whatever costs are necessary to raise the child. Chom has encountered a problem with one teacher at school who seems to view both her and her granddaughter with suspicion because the child's father died of AIDS. Chom plans to lodge a complaint to the principal regarding this. Chom deeply feels she is the person who most loves the child and who will provide the best care for her. She is determined to keep custody of the child and apparently would be willing to fight legal battles, if ever challenged.

As these examples illustrate, there is a considerable range in the willingness and determination with which grandparents assume their role as foster parents of AIDS orphans. Some are determined, even before their adult child's death, to take on the responsibility. Others appear to inherit the responsibility in an unplanned fashion, more as a result of circumstances beyond their control than anything else and, in still others, the fostering of the grandchild is done only reluctantly. Grandparents may take charge of the grandchild even when there is a surviving parent and even when that parent is not HIV-positive. This can arise either because the grandparents do not want to let the grandchild go or because the surviving parent does not want to be burdened with the child. In case 8, the determination to keep the grandchild was a way for the grandmother to remain connected to her son after his death and to deal with the grief. This is consistent with the observation by Longman (1995) in the US that parents of adult children who die of AIDS make continuous efforts to remain connected to them. In cases where the spouse of a co-resident ill son/daughter has already died or where the spouse deserted or does not want the children, fostering will almost automatically fall to the parents of the deceased. Such cases could force parents to take responsibility for the grandchildren even if they are in financial difficulties. In other cases, fostering may be shared if the ill son/daughter's spouse is still alive and continues to co-reside with his/her parents-in-law.

Witnessing negative reactions to grandchildren or helping solve problems such as those at school due to the fact that the grandchild is an AIDS orphan (as evident from illustrative cases 6 and 8) represent the main area in which any sustained negative community reaction was reported as a result of losing an adult child to AIDS. Most of those who

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had fostered a grandchild as a result of the parent dying of AIDS did not mention that the grandchildren were stigmatized or discriminated against.

As the illustrative examples suggest, the degree of determination and willingness to foster the grandchild was likely to be conditioned by the grandparents' financial status. If the grandparents were well off, they appeared to be more likely to foster willingly. Poor grandparents could end up fostering the grandchild if there was no other viable option, even if they were not eager to take on the responsibility. For those who had to keep the grandchild because they had no other choice, the added cost of food, clothes, school fees, allowances and other expenses associated with raising a child could add noticeably to their financial hardship. In addition, if the grandchild was infected with HIV, medical costs and the need to provide care could create a particularly difficult situation for the grandparent.



## V. Conclusions

Open-ended interviews in Thailand, with parents whose adult son/daughter died of AIDS, reveal the circumstances that lead to parental caregiving, the tasks involved and the stress they created. They also show how parents coped with this stress, and the consequences for their emotional, social and economic well-being. The results make clear that routine caregiving to individuals with AIDS often requires extensive time from the main caregiver. Caregiving is especially needed during the final stage of illness when the AIDS-afflicted person must often depend on caregivers for assistance with basic bodily needs and functions. Financial demands can also cumulate to a point where the resources of the adult son/daughter, as well as those of the parents, are exhausted. Such a situation can be overwhelming for any single individual, but it is particularly so for an older person. One frequent solution adopted by Thai parents, which meets with varying degrees of success, is to solicit the help of others in the immediate family in the form of assistance in caregiving tasks, paying expenses, and providing emotional support. In addition, viewing their role in terminal-stage caregiving 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 the child for becoming infected are important ways that help Thai parents cope with the emotional stress of taking care of their terminally ill child.

The experiences and consequences revealed are partly influenced 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

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serious epidemics. Theravada Buddhism—the predominant religion in Thailand—exerts a major influence on the prevailing value system and on how Thais view social and family relations (Keyes 1987). It seems likely that the strong value placed on non-interference in the affairs of others is linked to the Buddhist emphasis on personal action and responsibility in achieving spiritual liberation. This, in turn, probably tempers the extent of negative community reaction to individuals with AIDS and their families, especially in terms of minimizing moral judgements about infected individuals. The availability of government health insurance and, to a lesser extent, welfare benefits, mitigates the economic impact in Thailand compared with many other developing countries with significant epidemics. At the same time, Thai parents have less protection against severe economic consequences than would be true in more developed economies where the available safety net of health and welfare measures is far more extensive. The relatively widespread knowledge, even among older Thais, about AIDS and how it is transmitted probably also distinguishes Thailand from many other developing countries and helps minimize anxiety about contagion among Thai parental caregivers.

Other features of the Thai situation, however, are probably shared in varying degrees by many other developing countries with AIDS epidemics. Perhaps most significantly, the profound emotional suffering that parents experience when witnessing the decline of their child's health and the child's ultimate death must be a universal phenomenon. Familial systems of intergenerational obligations, such as those that persist in Thailand, are found in many societies in the developing world. As in Thailand, they typically involve exchanges of services and material assistance throughout the life course, including parents co-residing with or living near their adult children (Cowgill 1986; Knodel and

Debavalya 1997; World Bank 1994). Although there is diversity in their specifics, parental residential care and support for grievously ill adult children can be accommodated relatively easily within these systems. Limited options for institutional and other forms of formal care and financial support for a person with AIDS further reinforce the tendency to depend on informal channels, such as parents and family members, in both Thailand and other developing countries.

Another feature common to Thailand and other countries with serious epidemics is the predominant role of heterosexual transmission of HIV, brought about mainly by marital intercourse and various forms of transactional sex. Marital sex is considered normal behaviour in all settings. Moreover, although the forms vary, transactional sex in much of Africa, as in Thailand, is generally tolerated (Caldwell, Caldwell and Quiggin 1989; Knodel et al. 1996; Peracca, Knodel and Saengtienchai 1998). The acceptability of these behaviours probably removes what could be an important barrier to turning to parents or returning to home communities for care, compared with settings where the underlying behaviours are morally disapproved of by large segments of the population, as is the case with homosexual relations and intravenous drug use in the US and some other Western countries. Under such circumstances, a fear of revealing a lifestyle that may not be accepted by parents or others in the home community can deter someone with AIDS from seeking parental care and support at the time of illness.

Still, as our interviews reveal, social stigma and the fear of it do exist in Thailand even if not to the same extent as elsewhere. The stigma seems to be based largely on fears of contagion from association with a person with AIDS (and, much

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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 with a strong focus on misconceptions about risks and that promote a sympathetic view towards persons with AIDS and their informal caregivers (especially their older-age parents who are responsible for so much of the terminal-stage care), could help improve the situation.

As our study of parental caregivers makes clear, parents are often intimately involved in all facets of their son/daughter's experience with AIDS, including 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 caregiving, including accurate and up-to-date information on availability and administration of appropriate treatments. Moreover, they have a strong will to seek help for their child in any way possible. Thus parents whose health permits them to be mobile within the community and beyond, are also well suited 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 AIDS caregivers and their potential in facilitating programmes directed at those with HIV/AIDS remain largely unrecognized. Educational programmes on AIDS home caregiving need to take into

account the important role of older-age parents. At the same time, the potential contribution parents can make towards effective implementation of existing programmes should be harnessed. This potential is likely to increase in importance as new, more ambitious programmes are undertaken. These new programmes are likely to provide more extensive prophylaxis and treatment for opportunistic infections and perhaps even complex antiretroviral treatment of HIV more broadly, in addition to promoting palliative care. Older-aged parents could play a key role in effectively implementing these new programmes. Parents not only have great motivation and dedication to improve the well-being of their infected adult children but, as our research shows, they are often the ones who accompany their ill son or daughter to health service outlets, stay with them when they are hospitalized, administer prescribed medications at home, and act as major caregivers in general. 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 ease a significant amount of parental distress by reducing the suffering of their sick child. Even more so, improvements in preventing or effectively treating HIV itself would serve parents by answering their ultimate wish to see their adult children continue to live a healthy life.

## Annex A.

### Data and methods

Data for this study come from 20 open-ended interviews, 18 involving the parents of adult sons/daughters who died of AIDS (13 with the mother only, 2 with the father only and 3 with both parents), one with a mother-in-law who was the primary caregiver of a daughter-in-law who died of AIDS, and one with grandparents who cared for a six-year-old grandchild who died of AIDS (and whose father, the son of the respondents, was HIV+ but still healthy). Table A-1 lists in greater detail the number of interviews according to the type of loss experienced by the interviewees. The actual number of losses is greater than the number of interviews because several cases involved multiple losses. When more than one person in the family had died of AIDS, the interview focused on the most recent one to die or the one for whom the caregiving role was more pronounced. The majority of cases referred to the loss of a son, reflecting the larger share of males among the AIDS caseload in Thailand. For example, according to nationally reported AIDS cases for 1996-98, 77% were male (UNAIDS and WHO 2000). Since the vast majority of those interviewed were parents who provided care to one or more of their adult children, for convenience we use the term parental caregiving to characterize the experience of the sample collectively, even though this is not strictly true in all cases. Likewise, we refer collectively to the older persons interviewed as parents, even though, in a few cases, they were parents-in-law or grandparents.

**Table A-1. Types of losses experienced by the interviewees**

Nature of loss	Number of interviews	Interview IDs
Single, divorced or separated son	7	B1 B2 B3 P2 P3 R4 R5
Married son	7	C1 C4 C5 P1 R1 R3 R7
Married daughter and married son	1	C2
Married son, daughter-in-law	1	C3
Son-in-law; infected daughter	1	C6
Married daughter	1	R2
2 married sons, 2 daughters-in-law	1	R6
Grandson (son is living with HIV)	1	R8

The interviews were conducted in mid-1998 and the first half of 1999. Three took place in Bangkok, six in Chiang Mai province in the upper north, three in the west central coastal province of Phetchaburi, and eight in Rayong province on the eastern seaboard. Based on HIV surveillance among military recruits between 1991 and 1998, HIV prevalence is moderately high in Bangkok (2.7%) and Phetchaburi (3.8%) and quite high in Rayong (6.5%) and Chiang Mai (7.6%), relative to the national level of 2.5% (data from Armed Forces Research Institute of Medical Sciences).

We judged 11 of the families interviewed to be of poor socioeconomic status, 6 to be moderate, and 3 to be well off, by local standards. With two exceptions, the individuals who died of AIDS apparently contracted HIV heterosexually. About half were married at the time of death. Most were seriously ill for only a few months before dying and only one was seriously ill for more than 6 months. In slightly more than half of the cases, the person who died lived with or nearby the interviewee from the time of initially becoming symptomatic. In one case, the parent moved in with the ill child. In the remaining cases, the child returned home after becoming ill and, in 3 cases, this occurred within just a few days or weeks of death. With only a couple of excep-

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tions, the interviewees were in their 50s and 60s. The fact that a substantial proportion of our cases involved adults who returned to their parental home after being ill, that some did so when they were close to death, and that the parental caregivers interviewed were in their 50s and 60s, mirrors the general situation in Thailand (Knodel et al. 2001).

Local community leaders and staff of a relevant NGO in Bangkok and local government health station personnel in the other three provinces helped identify potential respondents. They also acted as intermediaries, contacting potential respondents in advance to ask if they were willing to be interviewed. Participation was voluntary. Respondents were asked again at the time of interview if they were willing to discuss the loss of an adult son/daughter with the interviewer. Reference was not made specifically to AIDS unless the respondent freely admitted that as the cause of death. Names, addresses or other identification were not recorded in order to maintain confidentiality. None of the respondents had been active in AIDS advocacy groups. The first author of this report conducted all the interviews except those in the northern province, where the interviews were carried out by two Thai colleagues who spoke the northern dialect.

Most interviews took place at the respondents' home to promote a private and relaxed atmosphere. Occasionally, reminders of the deceased son/daughter around the house, such as his/her picture, a funeral urn with his/her ashes, or the room or corner where he/she lay during the terminal stage of illness, evoked emotional reactions as the interview proceeded. The interviews followed a common set of guidelines, developed and pre-tested at the onset of the study, covering numerous issues relating to the illness and death of the individual (see Annex B). These issues included care-



giving, health beliefs and knowledge related to AIDS, expenses during the illness and their impact on the respondents, how expenses were financed, the role the deceased child had played in the family economy, fostering of grandchildren left by the deceased, community reaction, and emotional reactions and support. Interviews were conducted in a conversational style and, with the permission of the respondent, were tape-recorded. Interviews typically lasted about two hours although, along with the depth of information provided, they varied, depending on the relevance of some issues to the case and how well the respondents could express themselves.

In two cases, respondents were reluctant to admit, and perhaps genuinely did not believe, that AIDS was the source of their child's death. Questions about beliefs and knowledge regarding AIDS and community reaction were purposely omitted in these cases. In each of these cases, intermediaries made clear that the actual cause of death had been AIDS and, indeed, the symptoms described by the respondents seemed to confirm this. However, to facilitate the interview, questions were rephrased in terms of caring for and losing an adult child to a prolonged illness, without referring to the cause of death.

All interviews were fully transcribed in Thai and translated into English. Both Thai and English language transcripts were used in the analysis. We coded transcript text segments in terms of topics and categories of interest. We utilized the Ethnograph software programme, designed to assist in the analysis of qualitative data, to expedite the retrieval of relevant segments for systematic topical review of the content of the transcripts (Seidel 1998). We coded transcript text segments in terms of topics and categories of interest to derive overview grids that provided a systematic summary of tran-

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script contents. This procedure facilitated judging how often particular aspects of the experience or situation related to parental caregiving arose in the interviews (Knodel, 1993). As with most qualitative research, however, we generally avoid attempts to quantify our findings beyond rough characterizations of frequency. To state findings in more refined quantitative terms would provide a false impression of precision, given the nature of the sampling and data-collection procedures.

The open-ended conversational style of the interviews permitted flexibility in the order and manner of asking questions. By providing the interviewees sufficient time to express their views and allowing the interviewer to probe for clarification or more detail, where necessary, the approach facilitated the understanding of situations that are often complicated and, for other reasons, not readily amenable to a survey format using closed-ended questions. At the same time, our study is based on a small sample of older persons who provided care, who expressed willingness to an intermediary to discuss their experience with us and, with the exceptions noted above, admitted that AIDS was the cause of their child's death. Notably absent, by design, are parents whose son/daughter spent the entire duration of the illness without their active involvement. Also, parents whose relationship with their adult child had been strained or whose experiences were particularly painful were probably less likely to agree to an interview. The impact on parents in such cases is probably different to that reported by cases included in our study. Thus, while our results cover a substantial range of situations that characterize the parents of adult children who die of AIDS in Thailand, they are unlikely to reflect the full spectrum. Nevertheless, the quantitative research we conducted in Thailand makes clear that parents who did not provide care are in the minority (Knodel et al. 2001).

Besides describing results in the text, we use three formats for presenting the data from our interviews in the following analysis: 1) in tables containing condensed summaries; 2) as more detailed histories of illustrative individual cases; and 3) as verbatim quotations from the interviews. The tables are intended to provide very brief overviews of specific aspects of the full set of situations that were represented in the interviews. The individual cases histories are intended to provide a fuller sense of the processes involved that lead to particular outcomes. The details are presented as they were related to us by the interviewees and, thus, necessarily reflect their particular viewpoint. Thus, the accounts may not always be strictly factual but they do at least capture the experience of parental caregivers as they saw it. The names of persons involved are fictitious to protect confidentiality. The verbatim quotations are intended to give a sense of how the interviewees saw particular aspects of their situation, in their own words.

We also use a reference code for each specific interview to enable the reader to link information about any particular case across the three modes of presentation. The reference codes simply start with the first letter of the province in which the interview took place (B for Bangkok, C for Chiang Mai, P for Phetchaburi and R for Rayong) and consecutive numbers to differentiate the interviews within the province. For each quotation, we also indicate the location, sex and age of the interviewee and the line numbers from the English language transcript from which it is taken. Sometimes the comments are extracted from a longer discussion, omitting intervening statements for the sake of brevity. Some of the quotations include reference to the national currency, the Thai Baht. The value of the Baht in terms of the US dollar fluctuated during the period covered by the interviews. For most of the time, one US dollar roughly equaled 30–40 Baht.

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To place our findings in the context of the broader population of parents who lost a child to AIDS, we draw on the Thai AIDS Cases Study (TACS), which provides quantitative information on caregiving and living arrangements of approximately 1000 cases of individuals living with, or who died of, AIDS (see Knodel, Saengtienchai et al. 2000 for a detailed description of the methodology and findings). The study systematically collected information from community health workers and other knowledgeable local informants during 1999 from 85 sites in eight provinces and Bangkok. In addition to basic information on living and caregiving arrangements (cited above) that was provided for the full set of cases, more detailed information about their circumstances was provided for a subset of almost 300 cases. While the TACS cannot claim to be nationally representative in any statistical sense, the cases reported closely resemble the national population of recent AIDS cases in Thailand on several important dimensions. They thus provide a reasonably typical sample for comparison on some of the issues examined in the present qualitative analysis.

# Annex B:

## Guidelines for interviews with parents of adult sons/daughters who died of AIDS

### **I. Introduction**

- A. Describe the purpose of the project and the visit.
- B. Confirm that interview is voluntary.
- C. Stress that the interviewee is free not to talk about any particular issue and/or to terminate the interview at any time.

### **II. Background characteristics**

- A. How long have you lived here?
- B. Who else lives in the house with you?
- C. Are you working?
  1. (If working): What is your job?
  2. (If retired): What did you do before retiring?
- D. How old are you?
- E. How many children did you have?
  1. Where are they now?
  2. What do they do?
- F. Did you go to school? How many years?
- G. How about your spouse? How many years of schooling did he/she have?

**III. Characteristics of the person who died of AIDS**

(Ask about most recent case if there is more than one AIDS death)

- A. How about (*name*)? Was he/she living here with you? (If he/she moved in):
1. Where was he/she living before?
  2. What kind of work was he/she doing before moving in with you?
  3. What prompted him/her to move in?
- B. Did he/she have a family/children?  
Probe: What happened to the family?

**IV. Daily routine for caregiving to person with AIDS**

- A. Please tell me about what happened during a typical day when you were caring for (*name*).  
Probes: What was your normal routine from the time you got up? What did you have to do to help care for (*name*)?
- B. How much time did you usually spend providing care during the day?
- C. How about on days that are not typical? Were there special things that you needed to do for (*name*), but perhaps not every day?

**V. Health beliefs regarding HIV/AIDS**

- A. What is the best way to help keep a person with HIV/AIDS healthy?
- B. What are the best treatments for their illness?  
Probes: What sort of things do they need to eat and do? What sort of things do they need to avoid eating and doing?

**VI. Knowledge about AIDS related to caregiving**

- A. Did you have to change bandages or handle any blood from *(name)*?  
(If yes): could you describe what you do with the bandages and/or blood?
- B. Did you have any concerns about giving care to *(name)*?

**VII. Special needs of the interviewee**

- A. What was most difficult for you in dealing with *(name)*'s illness?
- B. What would have helped you the most in your caregiving?

**VIII. Financial impact related to illness and/or death of the person with AIDS**

- A. Did you have many expenses associated with the care of *(name)*?
- B. What sorts of things did you have to pay for?  
Probe: How about medicines, travel expenses?
- C. How much do you think you are spending on these things per month?
- D. Did caregiving interfere with working?
- E. How much were the funeral expenses?  
Probe: How did you pay for the funeral?
- F. Have the expenses associated with the care of *(name)* caused economic hardship for your family?  
Probe: Can you explain?

**IX. Sources of financial support for caregiving of person who died of AIDS**

- A. Did you have to pay for some of these expenses yourself?
- B. (If no):
  - 1. Who pays for the care of (*name*)?
  - 2. Is this a hardship for them?
  - 3. Are there others who help?
- C. (If yes):
  - 1. Where does the money come from?
  - 2. Have you had to take on (extra) paid work to pay?
  - 3. Did you have to sell any of your assets?
  - 4. Did anyone else help you pay for the care of (*name*)?  
Probe: How much did they help?

**X. Loss of financial support from person who died of AIDS**

- A. Did (*name*) help support the household before becoming ill?  
Probes: Did s/he provide help in the business or on the farm; help in household duties; send remittances (if he/she lived away from home)?
- B. (If yes): Has the loss of this support affected your economic situation?
- C. What other sources of income and support do you have?

**XI. Fostering of grandchildren**

- A. (If person with AIDS had children): Who takes care of (*name*)'s children?
- B. (If interviewee does):
  - 1. What type of expenses are involved in caring for the grandchildren?
  - 2. How much do you spend on this per month?
  - 3. Does anyone help you with the costs or care of the grandchildren?



- C. (If someone else is the primary grandchild caregiver):  
Are you involved in raising the grandchildren?  
Probe: (if yes): How so?

## XII. Community reaction

- A. Did your neighbours know or suspect that (*name*) had AIDS?  
(If yes): how did they react to it?
- B. Have your relationships with your neighbours changed since (*name*) became ill?
1. How were things with the community while (*name*) was still alive?
  2. How about after (*name*) died?
- C. (If the deceased had children): Were (*name*'s) children accepted by the community during the time that (*name*) was sick?  
Probe: How about after (*name*) died?
- D. What was the response of community leaders (e.g., headman, health officials) during the time that (*name*) was sick?  
Probe: How about after (*name*) died?

## XIII. Emotional issues related to person who died of AIDS

- A. Could you confide in someone about the difficulties of caring for (*name*)?
1. (If yes): With whom could you talk?  
Probe: What issues did you usually discuss?
  2. (If no): How did you handle matters?
- B. How are you coping with things since (*name*) died?

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UNAIDS both mobilizes the responses to the epidemic of its seven cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to HIV on all fronts: medical, public health, social, economic, cultural, political and human rights. UNAIDS works with a broad range of partners—governmental and NGO, business, scientific and lay—to share knowledge, skills and best practice across boundaries.

With AIDS claiming the lives of millions worldwide, little attention has been given to those indirectly affected by the epidemic. Yet uninfected family members can be affected emotionally, economically, socially and physically by the illness and death of a person with AIDS. This is particularly true for older parents who often become the caregivers of adult sons or daughters with AIDS.

The most extensive research in this area has been carried out in Thailand, where a study of 750 individuals who died of AIDS in 1996–1999 shows that their primary caregivers were their parents. Based on that research, this case study provides a qualitative analysis of the circumstances and consequences of parental caregiving to adult children with AIDS in Thailand, based on open-ended interviews. The study reveals the circumstances that lead to parental caregiving, the tasks involved and the stress created, how parents cope with this stress, and the consequences for their emotional, social and economic well-being. Issues of stigma and discrimination are also explored, together with educational programmes aimed at facilitating the role, and easing the burden, of parental caregivers.



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