THE IMPACT OF AN ADULT CHILD'S DEATH DUE TO AIDS ON OLDER-AGED PARENTS :

RESULTS FROM A DIRECT INTERVIEW SURVEY

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PREFACE

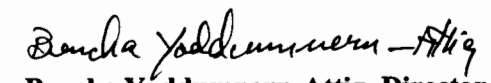
This is the third of a series of reports to come from the project "Socio-demographic Impact of AIDS on Older Persons", funded by the National Institute on Aging, the U.S. National Institutes of Health (Grant AG15983). The project is a collaborative one between the Population Studies Center, University of Michigan, the Department of International Health and Development, Tulane University, the Institute for Population and Social Research, Mahidol University, and the Faculty of Nursing, Chulalongkorn University. The principal investigators are John Knodel, Wassana Im-em, Chanpen Saengtienchai, Mark VanLandingham and Jiraporn Kespichayawattana. The overall project goal is to assess systematically how and to what extent the older population (age 50 and above) is being affected by the HIV/AIDS epidemic in Thailand. More specifically, the project seeks to determine the number and proportion of older persons who will suffer the death of an adult child to AIDS before their own deaths; the frequency, type, and severity of the consequences experienced by older persons who do experience this event; and the knowledge, attitudes and practices (KAP) of older persons related to AIDS, including care-giving practices.

We pursue these aims using a variety of data collection and analytical techniques. These include a key informant survey, a KAP survey, a self-administered survey of persons with AIDS, extraction of data from AIDS related welfare applications, a direct interview impact survey, open-ended interviews, analysis of existing survey data regarding older persons, the use of standard demographic analysis techniques and microsimulation. The present report is based on a direct interview survey of older-aged parents whose children died with AIDS.

FOREWORD

This is the third research report from a multifaceted study on how AIDS affects older person in Thailand. As the worldwide HIV/AIDS epidemic continues, there is increasing recognition that concern needs to broaden beyond the infected individual themselves. So far little attention has been paid to AIDS parents other than recognition of their responsibility as grandparents for caring for the AIDS orphans. This projects attempts to explore in details the issues related to the impacts of AIDS on the elderly people combining quantitative and qualitative approaches. The first phase of the project covered the two-year period from 1998-2000 followed by the second phase of the project, which is ongoing until now.

The overall project is a collaborative research involving the Institute for Population and Social Research, Mahidol University (the first phase); the Faculty of Nursing, Chulalongkorn University (the second phase); the Population Studies Center, University of Michigan; and Department of International Health and Development, School of Public Health and Tropical Medicine, Tulane University. This report series sheds light on how well older persons in Thailand are prepared to confront the epidemic, and the various ways that they are affected by it.



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The data collection for this project took the valuable time of many people. Most of all we owe our gratitude to the respondents who willing answered long series of questions. We also express our deep appreciation to the public health and provincial public health offices and health stations in Chiang Mai, Rayong, and Phichit provinces who helped arrange for field sites and to the village health volunteers who guided us to the houses of respondents and introduced us to them. Kullawee Siriratmongkhon provided effective project coordination throughout. She was joined by Sawitri Thayansin in helping supervise and in participating in the fieldwork and data processing. Finally we thank Yupin Angsuroch for her skilled help in supervising data entry.

ABSTRACT

The present report describes the methodology and findings of a direct interview survey in Thailand of parents of deceased adult children who died of AIDS and a comparison group of older age parents who had not suffered such a loss. The results provide extensive information on living arrangements; parental caregivng; health Impacts; spouses and orphaned children; care, treatment and funeral expense; longer term economic impacts; and community reaction. The detailed results of our survey show considerable diversity in the extent parents are impacted. Clearly personal caregiving and instrumental assistance by parents, especially the mother, can be very demanding. Even when a parent is a main caregiver, other family members, particularly other adult children, often assist the parental caregiver. Parents also often serve as critical links between their ill adult child and the health care system. Care giving often takes a toll on the emotional and physical health of the parental caregiver at the time care is being provided. Only a minority of the AIDS parents had fostered grandchildren left behind by their deceased son or daughter. Overall, the loss of a child to AIDS has a serious economic impact for only a minority of AIDS parents. At the same time, the poor appear to be the most adversely affected. Sustained social stigma directed at parents of persons who died of AIDS is far from universal in Thailand at present. Sympathetic and supportive reactions from others in the community are more frequently reported than negative ones.

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INTRODUCTION

The impact of the worldwide HIV/AIDS epidemic extends well beyond persons with HIV/AIDS themselves. Non-infected family members are especially vulnerable and can be affected emotionally, economically, socially, and physically by the illness and death of another member with AIDS. There is considerable recognition of the plight of AIDS orphans, the children of persons who die from AIDS. However, those who become ill and die of AIDS also have parents who survive them. Since persons with AIDS typically are in their 20s, 30s and 40s, their mothers and fathers are typically in their 50s, 60s and 70s. These AIDS parents, as we refer to them, represent one of the largest groups of persons who are seriously impacted by the epidemic. Yet despite the fact their adult child's illness and death can affect them in many consequential and adverse ways, they have attracted little attention from international organizations, national governments, and non-governmental organizations that deal with the AIDS epidemic.[1]

So far there is little research on the impacts of the epidemic either on older aged persons in general or more specifically on the parents of those who succumb to AIDS. To redress this situation we have undertaken a comprehensive study of AIDS and older persons in Thailand that incorporates both qualitative and quantitative research approaches.[2] As part of the study, we conducted a survey in which we directly interview AIDS parents and a comparison group of similar aged parents from the same survey sites who did not experience any recent loss of an adult child. The survey utilized a structured questionnaire that was designed to produce detailed data suitable for quantitative analysis. This report presents the findings of the direct interview survey.

The report begins by reviewing background information on the Thai epidemic and the main social, economic and cultural features of Thai society that are relevant to understanding the impact of an AIDS death on older-age parents. We then describe the design of our survey, placing it in the context of the broader methodological challenges faced by any attempt to gather information on AIDS parents. The main section of the report presents the survey findings. They are organized according to the following topics:

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[1] One notable exception is HelpAge International which regularly refers to this issue in their newsletters and conferences.

[2] For an overview of the project plan and design see (VanLandingham, Knodel, Im-Em, and Saengtienchai 2000). Earlier findings based on other project components have been reported in a series of research reports and articles. See (Wachter, Knodel, and VanLandingham forthcoming; Wachter, Knodel, and VanLandingham 2002; Saengtienchai and Knodel 2001; Im-em, VanLandingham, et al. 2001; Knodel and Chayovan 2001; Knodel et al. 2001; Knodel, Saengtienchai, Im-em, and VanLandingham 2000).

parental caregiving; health impacts; spouses and orphans of those who died; economic effects; and community reaction. We conclude the report by highlighting some of the key findings and commenting on their programmatic implications.

The Thai setting

The AIDS epidemic. Thailand is well suited for a study of the impact of AIDS on older persons in a developing country context. The AIDS epidemic there is of the longest duration in Asia (UNAIDS and WHO 1998; MAP 1998) and thus sufficient time has passed for many of the repercussions to be apparent. Moreover, after an initial period of some hesitancy, the Thai Government has openly confronted the epidemic in recent years helping create an atmosphere conducive to objective research on the epidemic's causes and consequences (Phoolcharoen, Ungchusak, Sittitrai, and Brown 1998).

Thailand's AIDS epidemic began in the early 1980s and took off rapidly. Only in the early 1990s, however, were large numbers of persons becoming ill with AIDS. By the mid 1990s the AIDS deaths were starting to mount in substantial numbers. Recent Thai government estimates indicate that at the start of 2000, almost 700,000 Thais were living with HIV/AIDS and that nearly 300,000 had died of the disease (Thai Working Group on HIV/AIDS Projection 2001). Although incidence has fallen in response to organized efforts to combat the epidemic, these same estimates project that deaths will hover around 50,000 a year for the next decade (Phoolcharoen et al. 1998; UNAIDS 1998). While an adult prevalence level of 2 percent is modest compared to the worst hit African countries, it still places Thailand second only to Cambodia in Asia (UNAIDS 2000). Moreover, levels have been much higher in some sub-regions, especially in upper northern provinces where over 15 percent of military recruits tested seropositive in the early 1990s and tens of thousands of deaths attributable to AIDS caused the overall death rate to more than double between 1990 and 1996 (Im-em 1999; Nelson 1998; van Griensven, Surasiengsunk, and Panza A. 1998).

In common with most moderate and high prevalence countries, heterosexual intercourse has been the dominant route of HIV transmission in Thailand (UNAIDS and WHO 2000). Much of the epidemic has been driven by commercial sex patronage, a behavior that, at least until the AIDS epidemic became serious, had relatively little social stigma attached to it in Thailand (Knodel, VanLandingham, Saengtienchai, and Pramualratana 1996). Thai society is generally noted to be relatively tolerant of some forms of sexual behavior, including prostitution and homosexuality, that elsewhere often evoke strong negative views among significant proportions of the population (Foster et al. 1995; Peracca, Knodel, and Saengtienchai 1998). More recently, infected men are increasingly spreading the virus to their wives and non-commercial partners (Chitwarakorn, Sittitrai, Brown, and Mugrditchian 1998). Almost half of new infections

are attributable to women infected by a husband or other partner (Thai Working Group on HIV/AIDS Projection 2001).

Socio-economic and demographic background. During much of the period associated with the AIDS epidemic, the country was also experiencing a continuation of the rapid economic growth that began several decades ago. However, Thailand was also at the forefront of the Asian economic crisis that came to a head in mid-1997 and spread almost instantly to many other countries in the region (Gragnolati 2001; UNDP 1999). In assessing the economic consequences of the AIDS epidemic, whether on a societal, familial or individual level, it is important to keep in mind that other influences including the turbulent economic situation are also having an impact.

Thailand is currently a low fertility country. The average number of live births a woman has, as indicated by the total fertility rate, has fallen from approximately 6 to 2 between the late 1960s and the early 1990s and has remained low ever since (United Nations 2001). This has important bearing both for the number of adult children that an older age parent has and the number of orphans who are left behind when an adult son or daughter dies of AIDS.

Intergenerational exchanges of support and services between parents and adult children are pervasive in Thailand as in much of the developing world, a situation which conditions the consequences of the loss of an adult child through AIDS or other illnesses (Knodel, Chayovan, Graiurapong, and Suraratdecha 2000; World Bank 1994). Widespread norms supporting filial obligations to parents, including old age support in the form of remittances and coresidence, underlie existing behavioral patterns (Knodel, Saengtienchai, and Sittitrai 1995). At the same time, parents typically feel a continuing obligation to ensuring their children's well-being. An important result of this system of intergenerational exchanges of familial support and services is that approximately half of adult children with a living parent aged 50 live in the same local community as their parents and half of these coreside in the same household with parents. Moreover, the vast majority of adult children who lived away from the parental community maintain contact. Almost 90 percent return to visit parents during a year and two-thirds of these visit at least several times.[3]

Thailand also has a well developed public health system for a developing country. Local health stations and district hospitals are widely accessible. In recent years affordable health insurance is offered though several government programs. These

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[3] The statistics cited are from original tabulations based on the Survey of Welfare of Elderly in Thailand (Chayovan and Knodel 1997).

include free medical care for persons age 60 and above, a voluntary low cost prepaid health card system that entitles up to five household members free access to government health services through a referral system, and a welfare program that covers medical costs for the indigent. In addition, employees of moderate and large enterprises have coverage through mandatory participation in the social security program instituted in 1994 and government employees have had their own health insurance scheme for many decades. Currently a program to provide universal inexpensive coverage is being implemented. Prior to late 2001, however, none of the various government health insurance schemes covered antiretroviral therapy (ART) for HIV although plans were being made to change this in the future.

Survey Design and Methods

General issues. Any survey of AIDS parents faces a number of logistical challenges related to the representativeness of the sample and accuracy or completeness of the results. Since many of the impacts of interest occur only at the late stage of the illness or following the death of the adult child, such a survey needs to target parents of adult children who have already died. Indeed, some potential long term impacts such as loss of old age support may not be evident until many years after the death. These very long term impacts may not be entirely evident until the parents reach the end of their own lives. At the same time, if the death of the adult child occurred in the distant past, parents may have difficulty recalling with accuracy the details about caregiving and other circumstances associated with the period of illness or the immediate post mortem period (e.g. the funeral). Thus the full range of impacts are very difficult to completely and reliably assess unless a longitudinal design is adopted in which the AIDS parents are initially interviewed shortly after the death of their child and re-interviewed after one or more intervals of time to assess the longer range consequences. Multiple waves of data collection, however, would require significant additional expenses and also be vulnerable to substantial loss to follow-up due to mortality of the older age parents, difficulty in locating those who survive, and a lack of willingness to be interviewed on such a sensitive topic more than once. Such a design would also delay for at least a number of years the time final results would be available.

One practical compromise is a cross-sectional survey that covers parents who lost an adult child to AIDS after enough time had passed for most impacts to be manifest but not so long ago that the respondent will have serious recall problems. Ideally, such a cross-sectional survey would interview a probability sample of AIDS parents. Typically this would involve at least two stages: first selecting a representative set of sample sites and second within each site selecting a probability sample of households, screening for AIDS parents who lost an adult child during some specified interval of time, and interviewing them.

There are several barriers even to such a cross sectional approach that made it impractical for us to pursue in Thailand. First, given the moderate HIV prevalence level and limited duration of the epidemic, only a small percentage of the general population of older persons so far has lost an adult child to AIDS. Under these circumstances, locating a sufficient number of AIDS parents through general samples of households in randomly selected sites is not feasible. Second, such an approach requires that a large proportion of parents be willing both to admit that they had experienced the loss of the child to AIDS and to be interviewed about it. Given the sensitivity of the issue, neither may be the case. Thus results could be seriously biased since those who would admit that their adult child died of AIDS and agree to an interview are likely to be selective among AIDS parents generally in ways that are associated with many of the outcomes of interest.

Survey design and implementation. Because of these difficulties we decided to select sites on a purposive basis and to rely on intermediaries to identify potential cases. For our survey, a site generally corresponded to the area of responsibility of a sub-district (tambol) government health center in rural areas and a municipality community health station in provincial towns. Within sites, however, we attempted to interview all AIDS parents we could identify except in several sites in Chiang Mai where the number of cases was too large to cover given our survey schedule. At these sites, we interviewed a systematic random sample of those listed.

Our selection of sites involved two stages. First we chose three provinces and then we selected localities within each province. To ensure some breadth in our coverage, we selected provinces from different sub-regions. In addition, we picked provinces where we had already collected data for other components of the project to ensure some consistency in coverage and to take advantage of contacts we had established in the provincial and local health system. The provinces chosen were Chiang Mai in the upper north, Phichit in the lower north, and Rayong on the east coast of the central region. Judging from the levels of HIV among army recruits and pregnant women attending antenatal clinics, as shown in table 1, HIV prevalence in Chiang Mai and Rayong are relatively high (for Thailand) while prevalence in Phichit is far more moderate.

Once we selected the three provinces, we contacted either the provincial health office (in Rayong and Phichit) or the district (amphoe) health offices (in Chiang Mai), explained the purpose of our survey, and asked them to assist in selection of tentative sites. We specified that the site should have health personnel who had been at the site sufficiently long to know of persons who died of AIDS over the last several years. In both Rayong and Phichit, we specified in our initial contact with the provincial health office that we wanted to include both rural and urban sites. Beyond that the initial selection of sites to visit was largely left to the judgement of the provincial or district health office liaison persons with whom we dealt. We then made pre-survey visits to

judge the suitability of each site and to list potentially eligible cases for interview. In Chiang Mai, we decided to only include rural areas because we were unable to find intermediaries who could identify cases at a local community level within Chiang Mai City (which is far larger than the provincial towns in the other two provinces).[4] However we purposely selected districts that ranged in distance from being quite close to being relatively far from Chiang Mai city.

Table 1 HIV levels and sample information by province

	Total	Province		
		Rayong	Chiang Mai	Phichit
HIV prevalence indicators				
% HIV+ among Army Recruits 1991-1998	n.a.	6.5	7.6	2.1
% HIV+ among antenatal care clients 1991-1997		4.9	4.3	0.9
Number of districts (amphoe) covered (a)	14	3	3	8
Number of sub-districts (tambol) covered (a,b)	41	12	9	20
Number of interviews				
AIDS parents	394	137	153	104
non-AIDS parents	376	136	143	97

Notes: (a) not counting one interview conducted in Amphoe Muang Chiang Mai
(b) since some sub-districts included two or even three health stations, the number of actual sample sites is somewhat higher than the number of sub-districts.

Source: HIV statistics are from Knodel, Saengtienchai et al. 2000.

In order to avoid the need for self-identification among AIDS parents, we relied on local health personnel to serve as intermediaries to identify AIDS parents (as well as the comparison cases of non-AIDS parents). We developed forms to list all known cases and the information we needed both to make our final selection and to guide the selection of comparison cases. During the pre-survey visit to each site, we explained the purpose of the survey to the intermediaries. In order to identify AIDS parents, we first asked the intermediaries to identify all adults who died of AIDS locally during the past three years. For the sites that maintained registers of deaths, we had informants systematically go through the registers to help identify AIDS-related deaths (regardless of the stated cause in the register). Elsewhere the informants relied on memory. To assist them in this task, we instructed informants to think about cases in each of the separate subdivisions of their

[4] We interviewed one case in the city during the preparatory period which we include in our data set.

area of jurisdiction one at a time. This proved a useful technique to jog their memory and encourage them to think more systematically about cases. In addition, at some sites, the health center staff asked village health volunteers to assist in the identification of AIDS deaths.

Once those who died of AIDS were listed, we asked the intermediaries to identify those whose parents lived locally. Local AIDS deaths are typically known, especially to health personnel, and they are usually familiar with most families under their jurisdiction. Thus the intermediaries seemed able to identify parents of persons who died locally of AIDS with minimum difficulty. It is possible, however, that they may have been less aware of cases who did not come to their health center for assistance. If so, the cases they could identify may have disproportionately excluded persons with AIDS from higher economic strata who could afford to use exclusively private health care services. We next asked them to identify persons who died of AIDS elsewhere but whose parents lived locally. This was much more difficult for them to do, since they are not necessarily aware of some or even most of such deaths unless the funeral was held locally. As a result, the list of AIDS parents eligible for interview disproportionately represented those whose deceased son or daughter either lived locally from before becoming ill or who became ill elsewhere but returned to the parental community before dying. We discuss the implications of this below.

In selecting cases of AIDS parents to interview, we gave priority to parents whose adult child died of AIDS more than 6 months prior to the survey (to allow for sufficient time for the consequences to be manifest) but not longer than 3 years earlier (to minimize recall problems). Given the history of the Thai epidemic this included most AIDS deaths that had occurred by the time of our field work. We also eliminated a small number of cases from consideration whom the intermediary believed would not agree to an interview. In several Chiang Mai sites where there were more eligible cases than we required, we systematically selected cases from the list using a set interval that would yield the desired target number. However, to partially compensate for the under-representation of cases in which the adult child died away from home, we attempted to interview all such cases in each site even when we were systematically sampling the others.

After setting a date to conduct the survey at the site, we asked the intermediaries to contact the persons we selected and request permission for an interview. The actual extent to which these instructions were carried out varied across sites. In some sites permission to be interviewed was only asked at the time of the survey. We also asked the intermediary to prepare a list of persons of comparable ages, marital statuses and economic backgrounds as the AIDS parents and who had a least one living adult child but who had not experienced any recent death among their children.

We instructed both intermediaries and interviewers to stress to potential respondents that the interview was voluntary. We also told them when explaining the nature of the interview not explicitly to mention AIDS specifically but instead to say simply that the survey was concerned with the consequences of suffering the loss of an adult child. In addition, no question in the survey specifically refers to AIDS nor was AIDS referred to during the interview unless respondents volunteered first that their child died of AIDS. We also informed potential respondents that all interviews were anonymous and confidential and no identifying information would be recorded. This avoidance of referring to AIDS and the insurance of confidentiality were intended to make the contacts and interview process less sensitive for those involved and thus to increase chances that AIDS parents would agree to an interview. In fact when asked the cause of death of their deceased son or daughter, in two-thirds of the AIDS parents' interviews, the respondent explicitly stated AIDS. Based on debriefings of interviewers, a substantial share of those who did not state AIDS as the cause of death still were open about the fact that their child had AIDS but gave as the cause of death some AIDS related symptom or illness (e.g. tuberculosis or fungal infection).

Interviews were conducted during late February and March 2000 in Rayong, in April in Chiang Mai, and in October in Phichit. The interview teams were all supervised by at least one senior project investigator and two permanent experienced project associates. The two associates were present at all three sites but the particular principal investigators varied with the specific site. We drew interviewers from different sources depending on the particular site. A total of 29 interviewers were employed for the survey. The survey supervisors including principal investigators also conducted some interviews. The team of interviewers for Rayong was drawn from a pool of experienced interviewers maintained by the Institute for Population and Social Research at Mahidol University in Bangkok. All were either currently studying at the graduate level or had bachelor degrees. Approximately half of the team for Phichit consisted of some of the same interviewers who were in Rayong and half were graduate students in nursing at Chulalongkorn University in Bangkok. About half of the Chiang Mai team was made up of students from the nursing faculty at Chiang Mai University and the other half from other faculties. All spoke the local (i.e. northern) dialect.

Each interviewer team received two days of training prior to the survey. The training stressed the sensitive nature of the interview in the case of AIDS parents. Interviewers were instructed to make sure the respondent was voluntarily taking part in the survey and were instructed to remind respondents that they could skip any questions that they did not wish to answer and could terminate the interview at any point. Interviewers were also instructed to adopt a sympathetic manner and, if the respondent appeared emotional or upset at any point during the interview, to pause and give them a chance to recover or talk in a more open-ended way about their experience. Interviewers

were monitored by supervisory staff to insure that they were able to deal sensitively with interviews with AIDS parents. After each day of interviewing the supervisors held debriefing sessions with the interview team to identify problems and share experiences. Techniques for dealing with respondents who became emotional during the interview were reviewed at these times. The impression of the supervisory staff was that almost all interviewers were sensitive to and dealt appropriately with respondents who became emotional. The one interviewer who was not dept in this way in his initial interviews was subsequently assigned only to interview non-AIDS parents.

As table 1 shows, our sample covers 41 different sub-districts (tambol) in 14 different districts (amphoe). The actual number of sites, defined in terms of health stations or related units for which we listed potential candidates for interviews and conducted the survey is somewhat larger since some sub-districts, especially more populous ones, had more than one such center and we occasionally included two or even three such sites in the same sub-district in our survey. The number of districts and sub-districts was highest in Phichit because AIDS was less common there and the number of cases per sub-district tended to be considerably lower than in the other two provinces. We conducted a total of 394 interviews with AIDS parents and 376 interviews with qualified non-AIDS parents.[5] We initially intended to interview roughly 100 cases of both AIDS and non-AIDS parents in each province but in both Chiang Mai and Rayong it was possible to conduct a greater number than planned because of the relatively large numbers of eligible cases we were able to identify at most sample sites.

The AIDS and non-AIDS parents that we identified for interview could be either a married couple living together or a separated, divorced or widowed parent. Table 2 indicates the distribution of type of the parental households interviewed and other information about the interviews. Almost two thirds of both AIDS and non-AIDS parent households involved coresident married couples. Most of the remainder (over a fourth) involved widowed, divorced or separated mothers and less than a tenth involved widowed, divorced or separated fathers. In cases of coresident married parents, we permitted both parents to participate in the interview. In over a third of the coresident AIDS parents interviews and in over a fourth of the interviews with married non-AIDS parents, both parents participated in the interview. In such cases, for the purpose of recording responses, one of the two parents was designated as the respondent and the

[5] The number of non-aids is somewhat less than AIDS parent interviews because we had to disqualify 20 of the interviews originally intended as cases of non-AIDS parents. In 19 of these disqualified interviews, the respondents reported that they had experienced a recent death of an adult child and in one case the respondent was childless. We also dropped one interview with an AIDS parent in which the interviewer mistakenly followed the skip instructions intended for non-AIDS parents.

other as the spouse at the start of the interview (regardless of who did most of the subsequent talking). For all cases of married couples, regardless of whether or not the other spouse was present, in somewhat over half, the mother served as the respondent.

In cases where both parents were alive and living together, certain items in the questionnaire were asked separately for each parent. Information on spouses of the respondent could be provided directly by the spouse if present or by proxy by the respondent. In this way, the interviews generated information for 649 AIDS parents (363 mothers and 286 fathers) and 621 control parents (345 mothers and 276 fathers).

Table 2 Circumstances of interview and number of parents for whom information was collected

	AIDS parents households	Non-AIDS parents households	All households (total sample)
N of interviews	394	376	770
Type of parental household			
(% distribution) coresident married couple	64.7	65.2	64.9
widowed, divorced, or separated mother	27.4	26.6	27.0
widowed, divorced, or separated father	7.9	8.2	8.1
total percent	100	100	100
Among married respondents:			
% with both parents present at interview	37.1	26.7	32.0
% who were mothers	54.5	51.8	53.1
Number of parents covered by interviews			
fathers	286	276	562
mothers	363	345	708
total	649	621	1270
Extent to which interview was emotional			
(% distribution)			
very emotional	11.9	0.5	6.4
somewhat emotional	36.8	10.0	23.8
not emotional	51.3	89.5	69.8
total percent	100	100	100

The median duration of an interview with an AIDS parent was one hour and with a non-AIDS parent 25 minutes. The difference reflects the fact that a large section of the questionnaire relating to the circumstances associated with the adult child's illness and

death were skipped in the case of interviews with the comparison group since these questions were inapplicable. The full questionnaire is reproduced as an appendix to this report.

In one sixth of the AIDS parents cases, the parents experienced the loss of more than adult child within the previous 5 years. In cases where there was more than one death, about half of the deaths other than the one we chose to focus on were also due to AIDS. In such cases, interviewers were instructed to select the most recent child who died of AIDS, excluding any child whose death occurred less that 6 months earlier, and use that child as the referent for questions referring to the deceased child.

We asked the interviewers to note at the end of each interview if the interview had been emotional for the respondent. Not surprisingly, for substantial numbers of AIDS parents the interview was emotional given that many questions concerned their deceased son or daughter. It is not possible to tell if their emotional reaction was related to the fact the child being asked about died of AIDS or simply because the child died. In any event, as table 2 shows, interviewers judged that almost half of the AIDS parents found the interview was at least somewhat emotional compared to only a tenth of non-AIDS parents. In a modest proportion of AIDS parents cases (12 percent), but in almost none of the comparison group, the interviewer judged that the interview was very emotional. Anecdotal reports from the interviewers and observations from the supervisors indicated that often respondents who appeared to experience strong emotion nevertheless welcomed the opportunity to share their experience with an interested and sensitive interviewer and in some cases took the opportunity to talk about their experience in an open-ended manner during pauses in the interview.

Response rates. Because the process of selection of non-AIDS parents as controls for interview was largely left up to the intermediaries and did not involve a listing of all potential cases, it is not possible to calculate a meaningful response rate for this group. In any event, of much greater interest is the extent to which we were able to interview the AIDS parents we identified given the sensitive nature of the issues to be covered in those interviews. Unfortunately, because of the somewhat complicated selection process and because of differences in the practices followed by the teams in the three provinces in recording information at each stage of the process(in part due to different types of data available), it is not possible to calculate exact response rates for AIDS parents for the survey as a whole. However, sufficient information exists for the Rayong survey to permit a reasonably detailed tally of outcomes for potential AIDS parents interviews:

1)	persons identified as dying of AIDS but for whom the intermediary had insufficient information to identify parents	14
2)	excluded because intermediary said the parents would be unlikely to grant an interview	3
3)	parents not at home at time of survey	14
4)	parents were too senile to interview	2
5)	parents refused to be interviewed	5
6)	not interviewed for unknown reasons	7
7)	successfully interviewed	137

There were also a small number of AIDS parents, not included in the above tally, who moved out of the locality during the period subsequent to the death of their adult child and hence were not eligible for interview. The Rayong results indicate that the refusal rate was rather modest. If we count both cases that refused when asked to be interviewed and those excluded before hand because of the intermediary's advice, the refusal rate is just under 6 percent ([item 2 + item 5]/[item 2 + item 5 + item 7]). This may somewhat understate refusals since there are some cases for which AIDS parents were identified but not interviewed for reasons which were not noted in the field records. It seems likely that most of these interviews were skipped because the team could not locate the designated respondents. However, to the extent that some may have been refusals that went unnoted, there is some ambiguity in how to best treat them in the calculation of the refusal rate. Even in the very unlikely case that all were refusals, the rate would still be under 10 percent. Calculating a response rate, rather than just a refusal rate, is also not completely straight forward because of a number of persons identified as dying of AIDS but for whom the intermediary had insufficient information to identify parents. In some of these cases, the parents were likely either dead or not living in the locality (and hence not eligible for inclusion in the survey). If we exclude these cases, the overall response rate in Rayong for AIDS parents was about 82 percent (137/168).

Although sufficient information is unavailable for Chiang Mai to calculate refusal and response rates in the same detail as for Rayong, the partial information that exists indicates that the refusal rate there was even lower than in Rayong.[6] The information available for Phichit is too incomplete to make a quantitative assessment but the recollection of the supervisors and the limited records that do exist indicate that

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[6] One difficulty in calculating response rats for Chiang Mai is that in several of the sample sites there were far more AIDS parents than could be identified. For efficiency of the survey, cases who seemed less likely to be available for interview including those who were difficult to locate were excluded before a systematic random selection was made from the remainder.

neither refusal nor overall response rates were particularly serious problems. The main problem was identifying sufficient cases given the far lower HIV prevalence in the province. Thus overall, despite the lack of complete documentation, we can say with some assurance that the large majority of AIDS parents who were initially identified and eligible for interview were indeed interviewed. Moreover, outright refusal, which would present the greatest threats to validity, was rare in part at least because of the procedures we implemented to reduce this potential problem as described above.

Sample biases. Since our survey was not conducted on a probability sample of either AIDS or non-AIDS parents, results cannot be generalized to the overall population in the way a nationally representative sample could. At least with respect to age, however, the AIDS parents we interviewed are distributed quite similarly to what we would expect from a representative sample. Although no nationally representative data exist for AIDS parents, we can derive an expected age distribution based on the information from the national AIDS registry and a 1994 household survey conducted by the National Statistical Office. The former provides the age distribution of adult AIDS cases; the latter provides information on the age of each household member and the survival status and age of his or her mother and father from a 1994 nationally representative household sample. By assuming that persons with AIDS resemble the general population at equivalent ages with respect to the survival status and ages of their parents, the expected age distributions of AIDS parents (at the time their adult child is diagnosed with AIDS) can be easily generated.[7] The results indicate that we should expect about 85 percent of AIDS parents to be aged 50 or older; 50 percent to be 60 or older, and 15 percent to be 70 or older. Results from our sample of AIDS parents are remarkable close: 87, 50 and 14 percent are at least ages 50, 60 and 70 respectively.

Despite having the expected age distribution, there is little doubt that our sample of AIDS parents under-represents those whose adult children died away from their parental community. As mentioned above, we attempted (and largely succeeded) to interview all such cases identified by the intermediaries. However, the use of local intermediaries to identify AIDS parents is almost certain to skew those identified towards

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[7] More specifically, the expected age distribution of parents of adults with AIDS was calculated from a matrix which showed the percentage age distribution of living mothers and living fathers for adults in each age group in the general population. This information was derived from original tabulations of the 1994 Survey of Elderly in Thailand (National Statistical Office no date). By weighting that matrix by the proportionate age distribution of adult AIDS cases in the national AIDS registry, we obtain the expected age distributions of living mothers and fathers assuming that the AIDS cases in each age group had living parents of similar ages as the equivalent age groups of adults in the general population. By combining mothers and fathers, we obtain the expected age distribution of parents.

parents whose child died in the same locality in which the parents resided. These parents are more likely to have been heavily involved in the caregiving and living arrangements of the deceased adult child than parents who lived locally but whose child died away from the sample site. As a result, the impact of the illness and death of the child with AIDS on the two groups of parents is likely to differ. In general, parents whose child died away from their locality are probably less vulnerable to some of the potentially adverse economic, time, and social impacts than those who lived with or nearby the adult child at the terminal stage. Moreover, they may well differ in other aspects of their relations with the child compared to parents whose child was in the same community at the terminal stage of illness. Additional potential biases could be present if willingness to be interviewed were be related to some of the outcomes under study or if intermediaries had only selective awareness of AIDS cases who died locally. However, under such circumstances, it is less obvious what the nature of the bias would be.

Some sense of the extent to which our sample of AIDS parents is skewed towards those who lived with and/or cared for their ill son or daughter is provided by a comparison with results from another component of our project, namely our key informant study. That component covered Bangkok and 8 additional provinces including the three provinces included by our direct interview survey. The informants typically were local health officials (similar to the intermediaries used in the survey).[8] They were asked to identify adults in the local area who were currently symptomatic or who had died of AIDS. We solicited basic information on living arrangements and caregiving for all cases, regardless of whether the parents lived locally, lived elsewhere, or were no longer alive. The study yielded information for over 1000 individual cases. Because of this, the key informant study is more broadly representative of AIDS parents in general than the direct interview survey. In addition, for almost 300 cases whom the key informants knew best, we asked additional, more detailed questions about the living arrangements and caregiving as well as some limited questions on aspects of the economic and social impacts on the family (Knodel, VanLandingham, Saengtienchai, and Im-Em 2001).

As we would expect, the key informant study indicates significantly lower rates of parental coresidence and caregiving than does our direct interview survey of AIDS parents. The key informant results find that a parent coresided with their ill adult child at the terminal stage in 70 percent of adult AIDS cases and was a main caregiver in 59 percent of the cases in which at least one parent was alive. Equivalent figures from the direct interview survey are 82 and 71 percent. Thus the direct interview survey results appear to be noticeably biased upwards in both respects. However, there is less reason to

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[8] For details of the methodology of the key informant study see Knodel et al. 2000.

expect that direct interview survey provides biased information about caregiving among those parents who were involved in providing care to their ill adult child. When interpreting results of the direct interview survey, this is important to bear in mind along with the likely biases described above. It is also the reason why much of our analysis focuses on the circumstances of parental caregivers.

Comparability between AIDS and non-AIDS parents. As noted above, our study design includes interviews with a sample of non-AIDS parents of similar age and socio-economic background as the AIDS parents we interviewed. The purpose of this design is to enable us to infer the impact of losing a child to AIDS by comparing the two groups with respect to certain outcome variables. Table 3 compares the basic background and household characteristics of the two types of respondents. The unit of analysis is either the entire household or the specific parent who acted as the respondent. Thus the number of cases are equal to the number of interviews.

Although the two groups are reasonably similar to each other, some modest differences are evident. Respondents who were AIDS parents are slightly older than those who were non-AIDS parents. AIDS parents have somewhat fewer living children on average than non-AIDS parents and are modestly more likely to have no living child or to have only one. Given that the AIDS parents are selected for having lost at least one adult child while the non-AIDS parents were selected for having not lost any child within the prior 5 years, it might seem odd that the difference in the average number of living children is considerably less than one child. There are at least two reasons that likely can account for this. fist, given that the AIDS parents are older than the non-AIDS parents and that fertility was declining during the past several decades, the non-AIDS parents went though their reproductive ages at a time when, on average, fertility decline was slightly more advanced.[9] Second, a key selection criterion for non-AIDS parents was that they not have experienced any child death during the past years. This will also bias selection towards parents with fewer children since the chance of losing a child increases with the number of children available to lose.

The AIDS parent respondents are somewhat less educated than the non-AIDS parents. Overall the AIDS parents' households are also less wealthy judging from household possessions. AIDS parents' households are modestly less likely to have a video player, a telephone, modern furniture, a motorcycle, or a car or truck. On the other hand, there is almost no difference between the two groups in the percent of households

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[9] For example, if we compare aids and non-AIDS parents who are over 60 with each other the average difference in mean number of living children is .44 rather than .33 for the entire samples.

Table 3 Basic background and household characteristics of respondents

	AIDS parents households	Non-AIDS parents households	All households (total sample)
N of respondents	394	376	770
Mean current age of respondent	62.2	60.8	61.5
Number of living children (a)			
(% distribution)			
none	2.0	0.0	1.0
one	12.2	5.6	9.0
two	20.8	22.6	21.7
three or more	65.0	71.8	68.3
total percent	100	100	100
Mean number	3.7	4.0	3.9
Educational attainment of respondent			
(% distribution)			
less than complete primary	29.3	22.7	26.0
complete primary	69.0	72.5	70.7
more than primary	1.8	4.8	3.3
total percent	100	100	100
% of households with			
color TV	92.4	92.6	92.5
video player	20.4	26.3	23.3
refrigerator	84.2	83.8	84.0
telephone	22.6	34.1	28.3
modern furniture set	24.7	35.1	29.8
air conditioner	2.0	3.7	2.9
motorcycle	73.5	78.7	76.1
car/truck	23.2	32.1	27.5
piped water	82.0	85.5	83.8
% of respondents and/or spouse who			
own house	89.8	94.1	91.9
own land	87.3	90.2	88.7
Mean number of Rai owned (if own land)	7.9	10.4	9.1
Household economic status			
(% distribution)			
better off	6.1	11.2	8.6
high middle	13.0	16.0	14.4
mid-middle	33.3	36.7	35.0
low middle	21.9	18.1	20.0
poorest	25.7	18.1	22.0
total percent	100	100	100
Insurance			
% with any health insurance	89.8	88.6	89.2
% with government health insurance	85.3	80.9	83.1

Notes: Results in this table refer only to the parent who served as the respondent or to the household of the respondent. respondents may be either the mother or father.

(a) Includes own, step and adopted children.

with a color TV or refrigerator. AIDS parents are slightly less likely to own their house and land and, among land owners, the size of holding is slightly less for AIDS parents than the comparison group.

In the survey, we asked each respondent to indicate their economic status relative to others in the community. In addition, we asked the interviewer to judge the economic status of each respondent based on the appearance of their house. We combined these two measures to obtain a measure of household economic status.[10] According to this measure, AIDS parents households are somewhat more skewed towards poorer households than those of non-AIDS parents.

The percent having some form of health insurance is similar for the two groups. AIDS parents households, however, are somewhat more likely to have government health insurance compared to those of the non-AIDS parents.

The somewhat less favorable economic indicators for AIDS parents compared to non-AIDS parents (i.e. with respect to household possessions, house and land ownership, and household economic status) could reflect the impact of the experience of losing a child to AIDS. The educational attainment distribution, however, is independent of any such effect. Given that AIDS parents tend to be less educated and education is usually correlated to economic status, it seems likely that overall the non-AIDS parents comparison group were probably better off that the AIDS parents even before the latter experienced the illness and death of their adult child. It is possible that this reflects a greater difficulty among intermediaries to identify AIDS cases from better economic circumstances as mentioned above combined with some laxity on the intermediaries' part in being strict about finding comparison households that matched in socio-economic status. Alternatively, it could reflect a lower tendency for persons of higher socio-economic status towards risk behavior leading to AIDS (again combined with laxity on the intermediaries' part in matching economic status when choosing controls).

As noted above, in the case of interviews that involved a married couple, we solicited some information about each parent (even if only one spouse was present at the

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[10] Each question allowed 5 different rankings from very well off to very poor. We assigned a score of 1 for very poor to 5 for very well off and summed the answers to the two items resulting in 9 possible scores ranging from 2 to 10. These scores were then grouped to form categories. In this table we show five categories but in later tabulations we group the sample into three categories. To determine the break points between categories we examined cross tabulations of the of summed scores and the percent of households possessing various appliances and motor vehicles. We chose break points that corresponded well with differences in terms of these percents.

interview). Table 4 compares the age, education, marital status, and work status of AIDS and non-AIDS parents. Each parent is treated separately as a unit of analysis regardless of who was the reference respondent. Thus the number of parents on which table 4 is based is greater than the number of interviews. Results are shown separately for mothers and fathers. The results with respect to age and education resemble those in table 3. Both AIDS fathers and mothers are slightly older on average than their non-AIDS counterparts and are somewhat more skewed towards lower levels of education than their non-AIDS counterparts. The marital status distributions of the AIDS and non-AIDS parents are very similar as are the percentage who worked last year.

In brief, our samples of AIDS parents and non-AIDS parents differ modestly with respect to age and socio-economic backgrounds although they are very similar in terms of insurance coverage, marital status and work status. Interpretation of differences in outcome variables between the two groups of parents needs to take into account these modest pre-existing differences in their backgrounds.

Characteristics of Deceased Adult Children

As described above, each interview with AIDS parents corresponds to one adult child who died of AIDS. Table 5 shows some demographic characteristics of the deceased children and compares them with comparable distributions derived from the national registry of AIDS cases maintained by the Ministry of Public Health. This registry is based largely on cases that are diagnosed at government hospitals. Although the registry is incomplete it nevertheless includes substantial numbers of cases and is the only source of national data available. We focus on reported cases for 1997-99 since most of the adult children in our sample died in these years (reflecting the selection process and the timing of fieldwork). Such a comparison reveals the extent to which our nonrandom sample differs from the population of interest on these key characteristics, each of which has potential relevance for the impact of the adult child's death on the older age parents.

A little over a fifth of the deceased adult children in our survey were women compared to a fourth of the national case load. Overall the distribution of our sample is somewhat younger than that in the registry undoubtedly reflecting the fact that, unlike the national caseload, our sample is limited to adults who have at least one surviving parent. Those whose parents are already dead will be older on average but would be necessarily be excluded from our survey. Just over four-fifths of the adult children in our survey were 25 to 39 years old when they died and two thirds were 25 to 34.

Table 4 Age, marital status, education and work status of AIDS and non-AIDS parents

	AIDS parents			Non-AIDS parents		
	Father	Mother	Both parents	Father	Mother	Both parents
N of cases	286	363	649	276	345	621
Age distribution						
under 50	4.9	11.1	8.4	12.4	20.3	16.8
50-59	25.6	35.7	31.3	30.5	31.7	31.2
60-69	44.9	35.7	39.8	37.8	32.6	34.9
70+	24.6	17.5	20.6	19.3	15.4	17.1
total percent	100	100	100	100	100	100
Mean age	63.5	60.2	61.7	61.1	58.9	59.9
Educational attainment (% distribution)						
less than complete primary	20.4	30.2	25.6	10.5	27.9	20.2
complete primary	76.1	68.7	72.0	80.4	70.9	75.2
more than primary	3.5	1.1	2.2	9.1	1.2	4.7
total percent	100	100	100	100	100	100
Marital status distribution						
married, living together	89.2	70.2	78.6	88.8	71.0	78.9
separated, divorced	1.0	5.0	3.2	1.8	3.2	2.6
widowed	9.8	24.8	18.2	9.4	25.8	18.5
total percent	100	100	100	100	100	100
% who worked last year	75.2	63.3	68.5	79.2	61.2	69.4

Note: In this table each parent is included regardless of whether directly interviewed or if spouse served as proxy for the information. Married persons living separately are treated as separated.

The distribution of our sample of deceased adult children and the national registry agree fairly closely in terms of the percent who are single. Both also indicate that the most common marital status is currently married. However, the proportion currently married in our sample is somewhat lower that in the national registry and the proportions separated or divorced as well as widowed are higher. This likely reflects, at least in part, the fact that the national registry refers to marital status at the time of diagnosis while our survey refers to the time at death. As our results below show, some marriages break up because of the illness (and hence after diagnosis). Also some who are diagnosed with HIV or AIDS become widowed between diagnosis and death.

Table 6 Social background characteristics of adult child who died of AIDS

	Total	Sons	Daughters
Total N of cases	394	311	83
Character (% distribution)			
good/normal, no qualifications	70.3	67.8	79.5
qualified good/normal	18.8	21.2	9.6
other	10.9	10.	10.
total percent	100	100	100
% who got along in the community	99.0	98.7	100.0
Education			
% for whom education is known	24.1	24.4	22.9
Percent distribution of those with known education	1.0	0.9	1.6
less than 4 years	71.6	72.3	68.8
primary 4-7	11.7	11.5	12.5
lower secondary	15.7	15.3	17.2
above lower secondary	100	100	100
total percent			
Occupation (% distribution)			
farmer, agricultural laborer, fisherman	21.3	23.2	14.5
non-agricultural laborer	21.8	23.8	14.5
transportation worker	10.7	13.5	0.0
skilled worker	11.4	12.2	8.4
sales worker	8.4	6.1	16.9
other non-agricultural employee	21.1	17.0	36.1
other/not working/ unknown	5.3	4.2	9.6
total percent	100	100	100
Among ever-married adult children, did deceased child have children			
(N of cases)	(278)	(197)	(81)
yes and one or more still alive	65.1	62.	71.6
yes but all are dead	4.3	4.6	3.7
no	30.6	33.0	24.7
total percent	100	100	100

About two-thirds of the deceased ever married adult children had at least one child who was still surviving at the time of the interview. Over a third, however, either never had children or all the children had died by the time of the survey. Ever married adult daughters were more likely to have surviving children than the ever married sons.

Living Arrangements

Residence at the terminal stage. Research based on earlier components of our project revealed that older Thais are extensively involved with their infected adult children through both living and caregiving arrangements. As noted above, the key informant study, which we believe is representative of a reasonably broad range of AIDS cases, indicates that that a substantial majority of adults who died of AIDS were living with a parent at the terminal stage of their illness.

Table 7 shows, based on our direct interview survey, where the adult child who died of AIDS lived at the time of death and who were members of the household at the time. The latter is important as it gives some idea of who was available for either personal caregiving or for instrumental help. As discussed above, the results are clearly biased towards situations in which the adult child lived with or nearby the parents at the time of death. Thus almost 90 percent of the cases covered in our survey either coresided or lived adjacent to parents and only 6 percent were living outside the community at the end of the terminal stage.

Despite the overall high level of coresidence, an association between marital status of the deceased child and final living arrangements is still apparent. Over 90 percent of the deceased single adult children covered by our survey resided during their last days with a parent compared to 72 percent of married children. In contrast, currently married adult children who died were far more likely to live adjacent to the parents' house than single children. This difference reflects customary living arrangements in Thailand. Although Thai elders typically live with a married child, a stem family norm prevails and rarely is more than one married child coresident (Knodel et al. 1995). Thus with the large family sizes of the current generation of older Thais, most married children eventually establish their own residence. However, married children who move out frequently establish their own household nearby or even within the same compound as either their own or their spouses' parents. Widowed, divorced or separated children who died were intermediate in both respects.

Table 7 Place of residence of the adult child who died of AIDS at time of death and resident members of household, by marital status at time of death

Where was the adult child who died of AIDS living at the time of death? (% distribution)	Total	Marital status at time of death		
		Single	Currently married	Widowed, divorced or separated
N of cases	394	116	167	111
In the parents' (respondent's) house	81.7	92.2	71.9	85.6
Adjacent to parents' house	7.4	1.7	11.4	7.2
In same locality as parent	4.6	2.6	7.2	2.7
Elsewhere	6.3	3.4	9.6	4.5
Total percent	100	100	100	100
Percent of households of last residence that included the following relatives				
Mother	80.1	88.7	71.9	83.6
Father	64.5	73.0	62.3	59.1
Spouse	31.1	--	71.9	1.8
Sister	41.1	52.2	36.5	36.4
Brother	26.8	38.3	24.0	19.1
Parent-in-law	1.5	--	3.6	0.0
Grandparent	2.6	2.6	1.8	3.6

Although the overall level of coresidence at the terminal stage of AIDS is undoubtedly over-estimated, the observed differentials by marital status are likely genuine. Single children would both be more likely to be coresiding with parents in any event and would be less likely than married children, whose spouses may caregiving needs as they arise, to have available viable alternatives arrangements to parental care.

Given that most of the persons who died were living in their parental home just before death, it is not surprising that overall the two most common persons to be living in the household at that time was the deceased child's mother and father. The fact that it was more common to live with the mother than the father mainly reflects the greater portion of cases in which a mother was surviving. However, in the few situations in which both parents were alive but living separately, there was a much greater likelihood that if the deceased child lived with a parent at the terminal stage, it was the mother (results not shown).[11]

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[11] For example, among the 13 cases of adult children who died of AIDS and lived with a separated or divorced parent, 2 resided with their father and 11 with their mother at the time of death.

Even for married children who died, the mother was the most common person to be in the household during the terminal stage, again undoubtedly reflecting the sample bias towards cases who lived with parents just before death. In most cases of married children (72 percent) who died, their spouse was also present at the terminal stage. Sisters and brothers of the deceased were also in a substantial number of households, but more so for single persons who died than for others.

Even among the few cases in our sample in which the adult child lived outside the parents' locality, a parent often was present in the household for at least part of the period of illness. Of the 25 respondents whose adult child was living outside the respondent's locality at the time of death, 19 (76%) spent time with the child after the child became ill (results not shown). Of those 19, 8 (42%) spent at least 1 month with the child during the period of illness.

While it was very common for the parental home to be the last place of residence for a deceased adult child, this did not mean that the child actually died there. As table 8 shows, two-thirds of the deceased adult children whose parents we interviewed in our survey died at the hospital. This was true whether or not the adult child was living with parents (i.e. in the respondents house) just before death. Most of those who did not die at the hospital died at the place where they were residing. This was slightly more common for cases in which the person who succumbed to AIDS was living with the parents than when living elsewhere.

Routes to coresidence. In understanding the high prevalence of coresidence and adjacent living arrangements at the terminal stage, it is useful to recognize that there are two basic routes that lead to the situation. In some cases the son or daughter already lived with or near the parents before becoming ill; in others, the adult child lived elsewhere when symptoms first appeared but returned to the parental community after becoming ill, typically because of the need for care. Both routes are substantial. As noted in the discussion of the Thai setting, about half of adult children of older-age parents live with or nearby them even under normal circumstances. Such residential proximity obviously promotes parental involvement during times when a son or daughter falls ill. In addition, substantial return migration of seriously ill adult children, especially in cases of a fatal and incurable disease such as AIDS, is frequent in the Thai context.

Analysis of the direct interview survey results indicates that 57 percent of the deceased children were coresiding with the respondent prior to becoming ill and only 29 percent were living outside the local area (results in this paragraph not shown in table).

This level of coresidence is far higher than would be expected from a representative sample of adults in the general population in the same age range reflecting the skewed nature of our sample. Of greater interest is that among those who lived with a parent at the terminal stage, almost a third (31.5 percent) had moved in during illness and almost 90 percent of those who moved in had come from outside the local area. The survey also confirms that the reason for changing residence was related to the illness. According to respondents who lived with a child at the terminal stage and whose child had moved in after the onset of illness, 87 percent said the son or daughter moved because of the illness. Clearly, return migration is an important route leading to parental caregiving.[12]

Table 8 Place of death of adult child who died of AIDS, by residence at time of death

	Total	Where resident at time of death	
		In respondent's house	Not in respondent's house
N of cases	394	322	72
Where person died (% distribution)			
At place of residence	29.7	29.5	30.6
In hospital	66.5	69.3	54.2
Other	3.8	1.2	15.3
Total percent	100	100	100

Parental Caregiving

Parents play a major role in caregiving to adult children with AIDS. Because of the biases in the sample discussed above, the percentage of parents who provided care as indicated by our direct interview survey are extremely high (91 percent of the persons who died were given at least some personal care by at least one parent). Our earlier research based on interviews with key informants, provides more realistic estimates: among adults who died of AIDS and who had at least one surviving parent, a parent assisted in personal caregiving for almost 70 percent and for almost 60 percent served as a main caregiver (Knodel et al. 2001). While the direct interview survey overestimates the percentage of AIDS parents who cared for an ill child, there is far less reason to expect that the results are necessarily biased about the conditions and nature of care

[12] For a more extensive analysis of migration associated with parental caregiving based on the full set of project components see Knodel and VanLandingham 2001.

provided among the large segment of AIDS parents who do provide care. Thus the analysis presented here is focused on parental caregivers.

Illness and caregiving duration. Table 9 indicates information about the duration and nature of the illness that led to the death of the deceased child. The mean duration between the first onset of symptoms and death was a year. The median, however, is less than eight months. This duration does not differ very much between adult children who had lived with the respondent since the onset of the illness and those who had either returned after the illness started or lived apart from the parents the entire time. Most cases experienced periodic bouts of illness rather than being continuously ill since the onset of symptoms. Again this did not differ between those who were resident with the respondent since the beginning of illness and those who were not. In a small minority of cases the illness was very brief or no symptoms were reported at all. Overall the period of serious illness requiring personal care was fairly short with the median only one month and the mean slightly under two months. Again little difference is apparent in this respect between cases in which the adult child was living with parents since the onset of symptoms and those in which the child was not.

Table 9 Nature and duration of illness, by residence at time of death

	Total	Was child who died living with the respondent since onset of illness	
		Yes	No
N of cases	394	220	174
Number of months between first onset of symptoms and death			
mean	12.0	11.2	13.1
1st quartile	3.0	3.0	2.0
median	7.5	7.0	8.5
3rd quartile	14.2	12.0	18.0
Nature or illness (% distribution)			
continuously ill	27.2	25.0	30.0
mixed periods of illness and improved health	62.8	61.4	64.7
brief or no illness	10.0	13.6	5.3
total percent	100	100	100
Number of months of serious illness prior to death requiring personal care			
mean	1.7	1.8	1.5
1st quartile	0.3	0.3	0.3
median	1.0	1.0	1.0
3rd quartile	2.0	2.0	1.6

Regardless of the route through which parental caregiving arises, its duration usually is a matter of months. Table 10 shows parental caregiving duration both for those adult children who were living in the parental locality before the onset of symptoms as well as those who returned after becoming ill. On average the duration of caregiving is modestly shorter for those who returned from elsewhere. However, for approximately a third of both groups, caregiving lasted less than a month and even for those who were in same community from the start, less than a fifth were given care for 6 months or more. The moderate duration of parental caregiving probably reflects a combination of short survival times after the onset of AIDS in Thailand and attempts on the part of many adult children to take care of themselves as long as they are able to do so. Although the duration of parental caregiving may be modest, it occurs during the most disabling stage of the illness and is thus likely to be intensive as well as very emotionally and physically draining for both parent and child.

Table 10 Parental caregiving duration, by return migration status of adult child who died of AIDS

	All cases	Return migration status	
		In parental locality before onset of symptoms	Returned to parental locality following onset of symptoms
Percent distribution of caregiving duration			
Less than 1 month	33.3	32.4	35.4
1-2 months	35.0	34.0	37.2
3-5 months	17.2	16.6	18.6
6-11 months	7.3	9.5	2.7
1 year or longer	7.1	7.5	6.2
Mean	2.9	3.1	2.5
Median	1.0	2.0	1.0
Number of cases	354	241	113

Gender differences. The direct interview survey provides information on who contributed to personal care giving during the terminal stage and whether or not the person was a main caregiver. For a modest number of cases, two persons shared the main caregiving role. Thus overall, in 71 percent of the cases at least one parent was considered to be a main caregiver (results in this paragraph not shown in table) but among these cases, in 12 percent both parents shared this role and in 16 percent a parent shared the role with someone other than his or her spouse. In the bulk of theses cases (i.e. the remaining 72 percent), however, a parent was considered the sole main caregiver.

Closely associated with personal care giving, is instrumental assistance outside the household (e.g. helping with transportation, shopping, or arranging for welfare benefits). We also asked specifically who provided the main share of such help. Overall, at least one parent was considered to be a main instrumental helper in 54 percent of the cases. Again in most such cases (79 percent), the parent mentioned was the sole main provider. Only in 7 percent of such cases did both parents shared the main role and in 14 percent a parent shared the role with someone other than his or her spouse.

There is a clear gender dimension to personal caregiving as table 11 shows. Mothers are more likely than fathers to provide personal care and are particularly more likely to be a main caregiver. To a small extent this reflects the fact that the adult children who died of AIDS were 20 percent more likely to have a surviving mother than a surviving father.[13] Thus the ratios of mothers to fathers providing care are somewhat lower when results are conditioned on having both parents alive compared to results based on all cases. Nevertheless, even for cases in which both parents were alive, the mother was 2.8 times more likely than the father to be a main care giver. Instrumental help shows far less pronounced gender differentials. When both parents are alive, fathers and mothers are about equally likely to provide some instrumental help and mothers are only 20 percent more likely than fathers to be the main provider of instrumental help.

Caregiving tasks. Caregiving to an adult child with AIDS can involve a wide variety of tasks ranging from some that likely would be done even for a healthy coresident 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 child develops contribute to diverse experiences among caregiving parents.

In the direct interview survey, if either parent gave any personal care or instrumental help to their deceased child, they were asked what specifically they had done. If a specific task was not mentioned spontaneously, the respondent was probed by the interviewer about it. When both parents were involved, the question referred to their combined efforts and did not distinguish between tasks done by each. Thus it is not possible to examine directly gender differences in specific tasks. However it is possible to

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[13] This is not very different than we would expect from a sample of the general population. Based on the age distribution of persons who died of AIDS as stated in the latest Thai national projections and information of the survival status and age of mothers and fathers of adults of different ages in the general population from a 1994 national household survey, we estimate that during the period 1996 - 2000 there is about a 25 percent greater likelihood that the mother than the father of an adult AIDS case to be still living.

distinguish among cases in which only a mother, only a father or both parents assisted. The results are shown in Table 12 in the order of the frequency with which they were mentioned. In a majority of cases in which only the mother or only the father provided assistance, the other parent was deceased (63 and 58 percent respectively - results not shown).

For the full set of parental caregivers, the most common task was watching over the ill adult child followed by food preparation. In a majority of cases, a parent had to help with very basic needs such as feeding, using the toilet, bathing and dressing. Several tasks involving instrumental help were also quite common, especially shopping for food and providing transportation for the ill son or daughter. Other instrumental help such as applying for welfare and managing financial affairs were relatively uncommon. The results show that parents are commonly involved in the interactions between the ill adult child and the health system, including transporting the son or daughter to health facilities, helping administer medicines and consulting with health care personnel.

Table 11 Percent of adult children who died of AIDS who received personal care or instrumental assistance among cases in which at least one parent provided the type of assistance specified, by gender

	Percent distribution (cases in which at least one parent provided the type of assistance specified)				Ratio of mother to father (a)
	Mother only	Father only	Both parents	Total percent	
All cases of assistance (including widows and widowers)					
Any personal care	37.6	8.1	54.3	100	1.5
Main personal caregiver	72.6	15.3	12.1	100	3.1
Any instrumental help	39.1	24.6	36.3	100	1.2
Main instrumental helper	58.9	34.1	7.0	100	1.6
Cases of assistance in which both parents were alive					
Any personal care	22.3	4.7	73.0	100	1.2
Main personal caregiver	70.0	15.0	15.0	100	2.8
Any instrumental help	25.5	27.4	47.1	100	1.0
Main instrumental helper	51.6	40.4	8.1	100	1.2

Notes: (a) [mother only + both parent]/[father only + both parents]

Table 12 Percent of parents performing specific tasks of personal caregiving and instrumental help among parents who assisted their adult child with AIDS by performing at least one activity

	Total	Which parent provided assistance		
		Mother only	Father only	Both parents
Type of activity				
Watching over	91.3	91.1	83.9	92.4
Preparing food	85.5	86.3	58.1	89.1
Shopping for food	78.3	80.5	58.1	80.0
Proving transportation, e.g. to clinic or hospital	74.7	67.2	58.1	81.5
Lifting and moving	72.4	68.5	54.8	77.3
Preparing and giving medicine	72.1	72.6	61.3	73.5
Feeding	67.8	66.1	51.6	71.1
Helping with toilet; changing soiled linens	66.9	63.7	41.9	72.5
Cleaning, laundry, doing dishes	66.8	71.0	32.3	69.5
Consulting with health care providers	65.1	65.9	38.7	68.6
Bathing	62.3	61.3	35.5	66.8
Dressing	60.7	62.9	38.7	62.6
Helping apply for welfare benefits	22.9	20.3	12.9	25.8
Arranging legal and financial affairs	16.9	14.8	22.6	17.3
Cleaning wounds	16.5	14.8	16.1	17.6
N of cases	366	124	31	211

Note: Excludes cases in which a parent did not provide either personal care or instrumental help.

Clear differences are apparent in the frequency with which most tasks were mentioned according to which parent provided assistance. For almost all tasks, the percentage mentioning doing the task is higher when both parents jointly assisted the ill child than when only one parent was involved. However, the percentage mentioning specific tasks was typically only modestly lower when just the mother was involved rather than both parents. In contrast, when just the father provided assistance, many tasks were substantially less likely to be done. Some caution is called for in interpreting the differences between cases in which only the mother and only the father provided assistance given the small number of cases of the latter.

Assistance to parental caregiving. Table 13 indicates who else helped when parents were involved in personal care giving and instrumental help activities. The table is limited to cases in which at least one parent assisted the adult child who died in the particular type of assistance specified. Parents were assisted by others in just over two thirds of the cases in which the parents gave personal care and in just over half of the cases in which the parents provided instrumental help. Assistance from others was somewhat less common in cases in which a parent was the main personal caregiver as well as when a parent was a main provider of instrumental help. This could reflect a selection process through which parents are more likely to become the main personal caregiver or provider of instrumental care if no one else was available to help.

The most common persons to help AIDS parents overall in their personal caregiving is one of their other children, i.e. a sibling of the deceased child. This occurred in just over half of cases in which the parent provided any care and in close to half of cases in which a parent was a main caregiver. Sisters (i.e. daughters of the AIDS parents) helped the parent almost twice as commonly as brothers in personal caregiving. In contrast, children of the deceased were uncommon as caregivers working with AIDS parents, reflecting both the fact most deceased adult children did not have any children of their own (see below) and the children they did have were too young to give care.

Table 13 Percent providing personal care or instrumental help in addition to parents, among cases in which parents assisted their adult child with AIDS in the specified type of assistance

Relation to person who died of AIDS	Personal care		Instrumental help	
	Parent gave any care	Parent main caregiver	Parent gave any care	Parent main caregiver
All (a)	68.5	61.6	52.3	42.1
Spouse	28.4	21.0	21.4	16.4
Any child	4.2	4.3	1.8	1.4
Son	2.2	2.5	0.7	0.5
Daughter	2.8	2.5	1.1	0.9
Any sibling	51.0	47.7	39.9	30.2
Brother	21.7	21.4	24.9	20.1
Sister	40.1	37.0	24.2	17.3
Other male	4.5	3.2	7.1	7.0
Other female	6.1	5.0	6.0	5.1
N of cases	359	281	281	214

Notes (a) Includes a small number of persons other than those listed above

Spouses of the deceased also helped in substantial numbers of cases. In almost 30 percent of cases where a parent gave any personal care and in just over a fifth of cases in which a parent was a main caregiver, the spouse of the deceased also gave care. If consideration is limited to deceased children who were currently married at the time they died, spouses provided at least some personal care together with the AIDS parents in two-thirds of the cases and thus were the most common person to share personal caregiving with an AIDS parent (results not shown). A clear gender difference is apparent, however, with 74 percent of wives of deceased sons sharing personal care giving with the parent compared to 43 percent of husbands of deceased daughters doing so (results not shown). Indeed the results in Table 13 indicate a similar gender difference is apparent for all categories of persons who shared personal caregiving with AIDS parents.

As with personal caregiving, siblings of the deceased were also the most common persons to share in providing instrumental help along with an AIDS parent, doing so in two-fifths of all cases where a parent was also responsible for instrumental help and in 30 percent of cases in which a parent was the main provider of instrumental assistance. However in this case, brothers and sisters were about equal in the percent of cases in which they helped. Spouses also assisted in a substantial number of cases. If consideration is limited to married deceased children, a spouse helped in just over half of the cases (results not shown). Again a gender difference is apparent, with wives more commonly helping parents who lost a son than husbands helping parents who lost a daughter (results not shown).

Health Impacts

The fact that many AIDS parents are in older ages makes them particularly vulnerable to physical strains associated with caregiving. In the direct interview survey, respondents were asked if they or their spouse experienced health problems during caregiving and were probed about a set of specific conditions. As table 14 shows, substantial proportions of parental caregivers reported each of the problems asked about. Almost three-fourths of parental caregivers reported experiencing nervousness or anxiety and over two-thirds reported insomnia, both suggesting that caregiving is accompanied by considerable mental and emotional stress. Over half of the parental caregivers also reported fatigue. Strained muscles as well as headaches and stomachaches were also fairly common being reported for sizeable minorities of caregiving parents.

The results in table 14 also reveal that overall among parental caregivers, mothers were more likely than fathers to report each of the health problems listed. To some extent however, this results from the greater involvement of mothers than fathers in personal caregiving, particularly as main personal caregivers. For both mothers and fathers, being a main personal caregiver, increased the chance of experiencing each of the

health problems, usually to a substantial extent. Differences in the percent experiencing each health problem are modest or virtually absent between mothers and fathers who were main personal caregivers. However, since mothers are much more likely to take on a main personal caregiving role, they also tend to be more likely overall to experience the health problems listed.

Table 14 Health problems experienced during caregiving by parents who gave care to an adult child with AIDS

Health problem	All parents who assisted with personal or instrumental care			Parents who assisted but were not main personal caregiver (a)		Parents who were main personal caregiver	
	Total	Mothers	Fathers	Mothers	Fathers	Mothers	Fathers
Strained muscles	41.4	49.1	30.7	45.6	25.3	50.4	41.9
Headaches/stomachaches	31.0	34.6	25.9	29.2	20.8	36.7	36.5
Fatigue	55.5	60.6	48.2	50.0	39.0	64.8	67.6
Insomnia	68.7	74.9	59.9	70.8	52.9	76.5	74.3
Nervousness/anxiety	73.4	80.3	63.9	75.3	60.1	82.2	71.6

Notes: (a) includes parents who were main instrumental helpers but not a main personal caregiver.

Comparisons between older aged parents who did not lose an adult child to AIDS (the control cases in the direct interview survey) with those who did suggests that for some AIDS parents, the experience of losing a child had a longer term detrimental impact on their health. Both groups were asked to compare their current health status with the situation three years ago. For most AIDS parents this would be before their adult child died (although in some cases the child would have been ill with AIDS at the time). Results are shown in table 15. Compared to control parents, AIDS parents were less likely to report that their health now was much better or somewhat better than three years ago and more likely to report that their health was worse or much worse. This holds both for mothers and fathers. The differences between the AIDS parents and the controls, however, is rather modest. Both groups were considerably more likely to report that their health worsened rather than improved perhaps reflecting the declining health with advancing age among both groups of older aged parents.

The experience of losing an adult son or daughter to AIDS is an emotionally wrenching experience which can lead to lasting grief and sorrow. Responses to questions about happiness in the direct interview survey appear to reflect this. Both AIDS parents and the control group who did not experience any recent death of a child were asked how happy they were at present and if they were more or less happy now compared to three

years ago. As the results shown in table 16 reveal, AIDS parents compared to the control group of parents are more likely to say they are unhappy at present and also more likely to indicate that their level of happiness has declined over the last three years.[14]

Spouses and Orphans

The illness and death of a married adult due to AIDS is likely to have serious repercussions on the deceased person's spouse and children which in turn may affect the parents and parents-in-law of the deceased. Considerable attention has been given to AIDS orphans, the children of the deceased, and to the fact that they may be fostered by their grandparents. [15] Much less attention has been given to the surviving spouses who are widowed by AIDS. Our survey provides information on both AIDS widows and widowers as well as on AIDS orphans and how their situations may impact on the parents or parents-in-law of the deceased person. However, since in the case of ever-married adults who died, our respondents are the parents of the deceased persons, their knowledge of the subsequent fate of their adult child's spouse is not always complete, especially in cases where separation or divorce occurred prior to the time of death.

Table 15 Percent distribution of self reported change in health over last 3 years, comparison between parents who lost a child to AIDS and parents who did not

	Both sexes		Fathers		Mothers	
Self reported change in health over last 3 years	AIDS parents	Non-AIDS parents	AIDS parents	Non-AIDS parents	AIDS parents	Non-AIDS parents
much better	2.2	3.7	1.8	4.0	2.5	3.5
somewhat better	8.2	10.0	7.0	6.9	9.1	12.5
about the same	31.0	34.2	37.5	39.3	25.9	30.1
somewhat worse	50.2	46.0	46.0	43.6	53.4	47.8
much worse	8.5	6.1	7.7	6.2	9.1	6.1
Total percent	100	100	100	100	100	100

[14] Since this question was only asked of the respondents themselves and not for their spouses the results are not tabulated separately for mothers and fathers.

[15] For the purpose of this discussion, we refer to any child who loses a parent as an AIDS orphan regardless of whether or not the other parent is still alive.

Table 16 Percent distributions of current state of happiness and change in happiness over last 3 years, comparison between control parents and AIDS parents

Measure of happiness	Control parents	AIDS parents
Current level of happiness		
very happy	8.8	3.8
somewhat happy	47.6	36.8
neither happy nor unhappy	27.4	34.8
somewhat unhappy	14.9	19.0
very unhappy	1.3	5.6
total percent	100	100
Change in happiness over past three years		
much happier now	3.5	2.3
somewhat happier now	21.8	17.5
about the same	42.8	34.0
somewhat happier then	28.7	38.6
much happier then	3.2	7.6
total percent	100	100

AIDS widows and widowers. Table 17 indicates information about spouses of the adult child who died of AIDS by gender of the spouse. As indicated above (see table 5), about one-sixth of the adult children who died of AIDS for whom our survey of AIDS parents provides information were either separated or divorced at the time of death. According to the AIDS parents we interviewed, the illness contributed to the marital breakup for a third of their separated or divorced sons who died and just over a quarter their daughters. They also indicated that in a substantial proportion of these cases the spouse who left returned to his or her own parents. This was particularly true for wives of infected sons. Thus the marital disruption associated with AIDS likely impacts not just the infected persons own parents but also the parents-in-law.

Among AIDS widows and widowers who were alive at the time of their spouse's death (i.e. those who were separated, divorced or still married to deceased adult child at the time of death), over a fifth are known to have remarried. Some of the surviving spouses who remarried were themselves HIV positive and in several cases also died of AIDS (results not shown). Overall, almost a fifth of the spouses of the adult children

Table 17 The situation of spouses of adult children who died of AIDS, by gender

	All spouses	Wives of deceased sons	Husbands of deceased daughters
Among cases of adult children who were divorced or separated at time of death			
N of cases	64	45	19
% for whom HIV illness contributed marital break-up	31.3	33.3	26.3
Did spouse return to parents after separation? (% distribution)	46.9	51.1	36.8
yes	26.6	24.4	31.6
no	26.6	24.4	31.6
unknown			
Among cases of adult children who were married, divorced or separated at time of death	231	178	53
N of cases			
Did spouse remarry? (% distribution)	22.5	23.0	20.8
Yes	52.5	53.9	47.2
No	25.1	23.0	32.1
Unknown			
Is spouse still alive? (% distribution)	66.2	71.3	49.1
Yes	18.6	15.7	28.3
No	15.2	12.9	22.6
Unknown			
Among cases of adult children whose surviving spouse subsequently died			
N of cases	90	47	43
Stated cause of death by parent-in-law (% distribution)	71.1	63.8	79.1
AIDS	20.0	23.4	16.2
AIDS like symptoms	8.9	12.8	4.7
Other/unknown			
Among cases of adult children whose spouse is known to be alive			
N of cases	153	127	26
Location of spouse relative to respondent (the AIDS parent) (% distribution)			
with or adjacent to respondent	18.3	18.9	15.4
same locality	19.6	21.3	11.5
elsewhere	62.1	59.8	73.1

who died were known to have also died themselves although the actual proportion is likely to be even higher given that the fate of a number of spouses are unknown. Moreover, a higher proportion of husbands of deceased daughters than wives of deceased sons subsequently died. In the majority of known deaths of spouses of deceased adult children, the death was attributed to either AIDS or AIDS like symptoms. The survey questionnaire did not include a question on where the spouses who died subsequently were at the time of their own death but it is quite possible many returned to their parental home either before becoming ill or once they needed care.

Among still surviving spouses of adult children who died of AIDS, almost a fifth continued residing with or living adjacent to their parents-in-law (i.e. the parents of the deceased spouse) and another fifth remained in the same locality. The remainder were living elsewhere at the time of our survey. There appears to be little difference between surviving wives and husbands in this respect. It was particularly common for those who lived adjacent to the deceased spouse's parents during the terminal stage of the spouses' illness to remain there (85 percent did so), probably reflecting the fact that the couple had established their own household; in contrast few (only 8 percent) who were coresiding with parents-in-law remained coresident (results not shown).

AIDS orphans. In considering the potential impact of AIDS orphans on AIDS parents in general, it is important to recognize that fostering a grandchild can only occur if the deceased adult son or daughter had surviving dependent children. According to our survey of AIDS parents, less than half (46 percent) of the adult children who died of AIDS had a surviving child of their own. The main reasons why the percentage is so modest is that a substantial share of the deceased adult children had never married (30 percent as indicated in table 5) and a substantial minority of the married children were childless at the time of death (either because they had not yet had children or because their children died). Moreover, most of the deceased adult children (71 percent) who had a child had only one, reflecting the low level of fertility in Thailand over recent decades. It is also important to recognize that even if both a husband and wife die of AIDS and leave orphaned children behind, there typically will be two sets of grandparents (both the maternal and paternal) who potentially could foster the grandchildren but at most only one set will do so.

Table 18 indicates the percentages of AIDS parents involved in care and living arrangements of AIDS orphans. Note that the unit of analysis on which the table is based is an AIDS parent and thus for those who are married each spouse is counted separately. Overall only 44 percent of the AIDS parents covered by our survey had a grandchild

orphaned as a result of the death of their adult child.[16] AIDS parents whose adult daughter died of AIDS, however, were far more likely to have an orphaned grandchild than parents whose son had died. This reflects the fact that almost all the deceased daughters had been previously married while over two fifths of the sons had not (see table 5).

Given that less than half of the parents in our survey had a grandchild orphaned by AIDS, it is not surprising that only a minority ever cared for an AIDS orphan. Again this percentage is far higher if the deceased adult child was a daughter than a son. Also, if consideration is limited to those AIDS parents for whom there was at least one surviving orphaned grandchild, just over two-thirds ever cared for the grandchild, almost sixty percent had ever had the AIDS orphan living with them, and almost half were currently living with an AIDS orphan. Even when conditioned on cases in which there was a orphaned grandchild, parents of deceased daughters are still more likely to take over care of the grandchild than parents of deceased sons.[17]

Caution is needed in interpreting the level of grandparental fostering indicated by the direct interview survey given a likely bias towards cases with grandparental involvement. Previous analysis of in-depth interviews suggests that the circumstances that lead to grandparental fostering of AIDS orphans are closely linked with the living and caregiving arrangements of the adult children with AIDS at the terminal stage of illness (Saengtienchai and Knodel 2001). AIDS parents who act as main caregivers to their ill adult child or who co-resided with or lived nearby (including cases in which the adult child returned to the parental home during the illness) are likely to inherit the responsibility for the ill child's offspring. As noted above, the selection of cases in our survey is almost certainly biased towards AIDS parents who lived with or nearby their deceased son or daughter and who provided care for them, i.e. those who are particularly prone to fostering orphaned grandchildren. Thus the survey results likely overstate grandparental involvement in care of AIDS orphans. Yet, despite this bias, when all AIDS parents are considered, only a fourth report ever living with an AIDS orphan and

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[16] This differs from the 46 percent cited in the previous paragraph since it refers to the percentage of parents with an orphaned grand child (i.e. the AIDS parents are the base population) while the previous paragraph refers to the percentage of adult children who had a surviving child (i.e. the base population is deceased adult children).

[17] This holds even when the spouse of the deceased adult child is still living (results not shown). Since the most common person taking responsibility for children left behind by the deceased person is the spouse in cases where a spouses is still alive (see next table), it is clear that surviving husbands are more likely to leave their child with the parent-in-law than are surviving wives.

only a fifth report currently doing so. Note, however, that this result represents the situation up to the time of data collection. It does not take into account the likelihood that a number of AIDS parents who are not currently fostering their grandchildren will likely do so in the future. The main reason for this is that some of the currently surviving spouses of the deceased adult child are caring for the children at the time of our survey are likely to HIV positive and to die on AIDS themselves before the children being cared for grow up.

Table 18 Percentage of AIDS parents involved in the care and living arrangements of AIDS orphans, by gender of deceased adult child

	All Aids parents	Parents of deceased	
		Son	Daughter
N of AIDS parents	349	515	134
Percent of AIDS parents whose deceased son or daughter had a surviving child	43.8	37.3	68.7
Percent of AIDS parents who ever cared for an AIDS orphan			
Among all AIDS parents	31.3	24.6	57.1
Among AIDS parents whose deceased son or daughter had a child	68.4	62.9	80.4
Percent of AIDS parents who ever lived with an AIDS orphan			
Among all AIDS parents	25.7	19.4	50.0
Among AIDS parents whose deceased son or daughter had a child	58.8	52.1	72.8
Percent of AIDS parents who currently live with an AIDS orphan			
Among all AIDS parents	20.8	14.8	44.0
Among AIDS parents whose deceased son or daughter had a child	47.5	39.6	64.1

Note: The unit of analysis for this table is an AIDS parent. In cases where both parents are surviving each counts as a case.

While table 18 examined fostering AIDS orphans from the perspective of the AIDS parents (i.e. the grandparents), table 19 provides information on AIDS orphans using the orphans as the base population. All together, the 394 adult children who died of AIDS and who are covered by the survey left behind 253 surviving orphans. Of these, more than half (139 or 55 percent) are known to have a surviving parent, the large majority of whom are the mother.

Table 19 Characteristics and living arrangements of surviving AIDS orphans

	All orphans	Is a parent still alive?			Among orphans with a surviving parent, sex of parent	
		Yes	No	Not known	Father	Mother
N of cases	253	139	87	27	25	114
Sex of orphan (% distribution)						
son	53.8	56.1	50.6	51.9	64.0	54.4
daughter	46.2	43.9	49.4	48.1	36.0	45.6
total percent	100	100	100	100	100	100
Current age of orphan (% distribution)						
0-4	22.7	28.3	15.5	16.0	20.0	30.1
5-9	42.9	38.4	51.2	40.0	56.0	34.5
10-14	19.0	19.6	16.7	24.0	24.0	18.6
15+	15.4	13.8	16.7	20.0	0.0	16.8
total percent	100	100	100	100	100	100
% who ever lived with the parent(s) of the parent who died (since the death)	54.9	48.2	66.7	51.9	56.0	46.5
Current living arrangement (% distribution)						
with parent(s) of the parent who died (a)	43.3	36.7	55.8	37.0	56.0	32.5
with surviving own parent (b)	25.8	39.6	0.0	33.3	24.0	43.0
with parent(s)-in-law of parent who died (b)	14.7	13.7	16.3	14.8	12.0	14.0
other	16.3	10.1	27.9	14.8	8.0	10.5
total percent	100	100	100	100	100	100

Notes: (a) includes some cases in which the surviving parent co-resides with or lives adjacent to the parent of the parent who died.

(b) may include some cases in which the surviving parent co-resides with or lives adjacent to their own parents (i.e. the parents-in-law of the parent who died).

Most of the AIDS orphans are still in dependent ages with over a fifth being under age 5 and two thirds under age 10. Since the death of the parent who died of AIDS occurred earlier (up to three or occasionally even more years before), the age distribution of the AIDS orphans at the time the parent died would be even younger. Approximately 55 percent of the orphans had ever lived with a parent of the parent who died. The differs, however, according to whether or not the other parent of the child was still alive, reaching two thirds of cases in which both parents are dead. Also, for children with a surviving parent, the child is more likely to live with maternal grandparents if that parent is the father than they are to live with paternal grandparents if the surviving parent is the mother.

Over two-fifths of AIDS orphans are currently living with the grandparents whose adult child died (the orphan's father of mother). Again this is considerably higher, reaching 56 percent, if both of the orphans parents are known dead. In cases where at least one parent survives, the child is most likely to still be living with that parent if the surviving parent is the mother but not if the surviving parent is the father. A substantial number of AIDS orphans also live with the parents-in-law of the parent who died, especially if neither of their own parents are surviving.

Many of the AIDS orphans are school age. It is thus of interest to examine the proportions who are actually attending school, especially since the literature about AIDS orphans in various parts of the world often suggests that AIDS orphans are sometimes prevented from attending school because either school administrators or parents of other students fear the AIDS orphans may be carrying the HIV virus and could infect other children. Table 20 shows the percentage of AIDS orphans who were currently attending school. The vast majority of children in the primary school ages of 6-12 were currently enrolled as were a large majority of orphans in the lower secondary school ages 13-16. Boy orphans were somewhat more likely than girls to be attending school in these ages, although give the small numbers of cases, especially for the lower secondary school ages, this may simply reflect chance variation. The very high attendance among primary school age orphans suggests that few AIDS orphans in Thailand are currently being excluded from school. Moreover we asked the reason for non-attendance for orphans between ages 3 and 16 who were not attending school. Only for two children did the respondent say the school did not allow the children to attend. In several other cases the respondents said that the child was too ill or weak to attend school. Overall the most common reason was financial difficulties.

Table 20 Percent of AIDS orphans attending school by age

Age	% in school			N of cases		
	Total	Boys	Girls	Total	Boys	Girls
3 - 5	66.6	63.0	69.7	60	27	33
6 - 12	94.7	96.9	91.8	113	64	49
13 - 16	82.6	90.9	75.0	23	11	12
17 - 20	29.2	26.7	33.3	24	15	9

Care, Treatment and Funeral Expenses

Illness and death from AIDS can involve a whole array of expenses associated with care and treatment as well as the costs of a funeral. If parents are involved in covering these expenses, or divert substantial time away from income generating activities in order to give care or make funeral arrangements, they may experience immediate and possibly longer term effects on their financial well being. The direct interview survey asked AIDS parents to provide considerable detail about the expenses they incurred in connection with the care, treatments and funeral of their deceased adult child. In addition, the survey explored the ways AIDS parents met these expenses.

Direct parental contributions. Results in table 21 indicate various dimensions of parental involvement in the expenses related to the care, medical treatment, and funeral of an adult child who died of AIDS. Results are shown according to the role played by parents as personal caregivers as well as their economic status. Because our sample is skewed towards cases in which the deceased child lived near or with parents at the terminal stage of illness, the results for the overall sample overestimate the level of involvement compared to what would be found for a more representative sample. As noted above, however, there is less reason to believe that results concerning AIDS parents who were involved in caregiving are particularly atypical of this substantial subgroup. Moreover, although the levels indicated for the different economic status groupings may be inflated, there is no obvious reason to expect that the pattern of the relationship with economic status is distorted.

Among our sample of cases, parents helped pay expenses for treatment and care during the period of illness for a very high percentage of adult children who died of AIDS (82% of the cases) and in over three-fifths (61%) they contributed a substantial amount (defined as 5000 Baht or over). In over three-fifths (63%) of the cases, a parent was a

main contributor to expenses during the period of the child's illness.[18] In situations where a parent served as a main personal caregiver, parental involvement in expenses is substantially higher than in cases in which the parents did not take on a main caregiving role. Economic status is also related to involvement in paying expenses for care and treatment. Compared to those of average or better off economic status, poorer parents were noticeably less likely to contribute to expenses and particularly less likely to pay a substantial amount or to be a main contributor.

Results in table 21 also indicate the percent of cases in which parents helped pay for specific expenses associated with care and treatment. The most common expense incurred was for food. In addition, in the majority of cases parents also helped pay for medicine, medical services including hospital fees, and transportation (presumably to health facilities). Among those cases in which a parent was a personal caregiver, the percent in which a parent was contributing to these types of expenses is noticeably higher than among cases in which a parent did not serve as a main caregiver. Consistent with overall levels of involvement in expenses, poor economic status is associated with lower percentages of cases in which parents contributed to each of these major aspects of care and treatment.

Funerals usually are major social events in Thailand. They typically last at least several days and involve treating guests to refreshments or meals. In addition, the expenses are very immediate occurring all at once unlike costs of care and treatment that are often spread out over the period of illness. The burden of paying for a funeral in Thailand is commonly mitigated by the customary practice of making monetary contributions towards expenses by those attending. Also many families belong to local funeral societies as a form or insurance. In return for making regular payments, a member receives a lump sum benefit when a death in the family occurs. In exceptional cases, funeral costs can be more than fully covered by some combination of contributions of those attending, funeral society benefits, and welfare relief for the funeral. Nevertheless, it is common for parents to incur net costs for the funeral of their deceased adult child. As table 21 shows, in almost three-fourths (74%) of the cases covered by the direct interview survey, the parents incurred net funeral costs and in over three-fifths (62%) had substantial net costs. Both situations were less common for cases in which a parent was not a main care provider. This may reflect a greater availability of others besides a parent to cover the funeral expenses in such cases as reflected in the fact others were also available to provide main care. Poorer parents were somewhat less likely than

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[18] As in the case of the main role in caregiving, respondents could state up to two persons as main contributors to care and treatment expenses. Thus in 9 percent of the cases in which parent was a main contributor, this role was shared with someone else.

Table 21 Involvement of parents in expenses related to care and funeral of adult children who died of AIDS, by caregiving and economic status

	All cases	Was parent a main personal caregiver?		Economic status		
		No	Yes	Better off	Average	Poorer
N of cases	394	113	281	75	131	187
% of adult children for whom:						
A parent helped pay expenses during adult child's illness						
any expenses	81.7	66.4	87.9	86.7	88.5	74.9
substantial expenses (5000+ Baht)	61.0	41.8	68.6	77.0	70.0	47.8
A parent was a main contributor to expenses during adult child's illness	62.6	38.9	72.2	71.6	67.2	55.4
A parent helped pay for:						
medicine	63.4	50.4	68.6	73.3	71.0	53.8
medical services/hospital fees	56.0	45.1	60.4	68.0	67.2	43.0
transportation	66.4	46.9	74.3	74.7	71.0	59.7
food	80.2	61.1	87.9	82.7	88.5	73.1
A parent helped pay for the funeral						
any net cost	74.3	63.6	78.5	76.0	83.1	67.2
substantial net cost (5000+ Baht)	62.0	49.1	67.0	70.7	71.5	51.4
Amount parents paid for care And treatment (in Baht)						
All cases						
Mean	33871	28569	35890	70590	32977	19437
Median	7500	3000	10000	20000	15000	3000
Parent was a main contributor to expenses						
Mean	48119	62767	44845	90205	42147	31312
Median	20000	15000	20000	30000	20000	9250
Net amount parents paid for funeral costs (in Baht)						
All cases						
Mean	18193	14298	19440	29154	20505	11611
Median	10000	2750	10000	16000	15000	5000
Parent paid at least some						
Mean	24488	22468	24790	38361	24682	17276
Median	15000	15000	16000	30000	20000	10000
Extent to which care and funeral expenses were a serious burden						
All cases	33.8	22.1	38.6	18.7	29.8	42.5
Parent paid at least some for care/funeral	38.2	28.4	41.5	20.0	32.2	50.6
Parent was a main contributor to care expenses	41.8	34.1	43.5	18.9	36.4	57.8
Parent was a main contributor to care expenses and had net funeral costs	45.6	43.8	45.9	23.3	43.1	62.5

better off parents to have a net cost, particularly a substantial one, probably reflecting their inability to afford an expensive funeral.

We asked respondents to tell us how much they spent in total for care and treatment expenses as well as the net amount they spent for funeral costs.[19] Table 21 includes these results. The distributions of the amount stated were typically skewed and thus we present both mean and median values. Although there are substantial difference between the mean and median values, the patterns of association with the caregiving role of parents and economic status are usually quite similar. Both mean and median values indicate that parents who were main personal caregiver incurred greater costs associated with caring treatment than those who were not. However if we limit consideration to parents who were main contributors to expenses, then the relationship between the amount spent on caring treatment is inconsistent and depends on which measure, the mean or the median, is examined. A clear association between the amount parents paid for care and treatment and economic status is clearly evident. This is so whether or not we limit consideration to only cases in which parents was a main contributor to expenses.

Overall, parents were somewhat less likely to incur net funeral costs than care and treatment costs but about equally likely to incur both if only substantial expenditures are considered. Based on mean values, the net cost to parents of the funeral was approximately half as much as the costs incurred in connection with care and treatment. However the median amount spent among parents overall is actually higher, reflecting less skewed distributions of funeral costs compared to care and treatment costs. The funeral costs incurred by parents was somewhat greater in cases in which a parent was a

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[19] When asking about these amounts (as well as when asking about amounts of money or time regarding other items covered in our questionnaire), we followed a two step strategy. We first tried to have the respondent provide a single amount. However in cases in which the respondent were unable to estimate a single amount, we probed if the amount was as much as a series of successive amounts (see question F4a in the questionnaire provided in the appendix as an example). This way we could determine if the amount spent was within particular ranges (either more than *x* but less than *y* or above the highest amount we stated in the probe). Most persons could state a single amount and among those who could not, most could provide an answer to these probes. For example, among those who incurred any expenses for care and treatment, exactly two-thirds were able to state a single amount, 31 percent could provide an answer that placed them within some range, and only 2 percent were unable to state an amount even within the broad ranges in the probe. Similarly, among those with net funeral costs, 83 percent stated single amounts and only 2 could not any information. In order to derive a single estimate for each respondent, we converted answers that were stated in ranges to the midpoint of that range except in the cases of respondents who stated the amount paid was above the highest asked in the probe. In those cases, we assigned a value that was equal to the mean of those who stated a single amount that was also above the limit of the highest range.

main caregiver than in situations in which a parent did not assume this role. Again a clear relationship between parents economic status and the net amount paid for the funeral is apparent whether or not we limit consideration to parents who paid at least some net amount for the funeral.

The amount paid for care and treatment as well as for funeral costs are substantial when compared to the prevailing per capita incomes. For example in 1996, the average annual per capita income in Thailand was about 76 thousand Baht. In the provinces in which we conducted our survey the equivalent figures were 30 thousand Baht in Phichit, 54 thousand in Chiang Mai, and 223 thousand in Rayong (UNDP 1999). The combined costs paid for care and treatment and for the funeral in our samples averaged 37 thousand both in Phichit and Chiang Mai and 97 thousand in Rayong among cases in which the parents incurred any direct costs themselves (results not shown).

In order to assess the financial impact on AIDS parents of the expenses associated with care and funerals, we ask them to indicate how serious a burden those expenses were for them. The results are found in the last panel of table 21. Approximately a third of all respondents indicated that the care and funeral expenses were a serious burden for them. If we limit consideration to those who paid at least something for care and funeral expenses, the figure rises 38 percent. For cases in which a parent was a main contributor to care and treatment expenses, over two-fifths (42%) of respondents said those expenses were a serious burden. Finally in cases in which a parents was both a main contributor to care and treatment expenses and had net funeral expenses, the portion who felt the expenses were serious burden starts to approach a half (46%).

There is a clear association between cases in which a parent was a main personal caregiver and a greater likelihood of reporting that the care and funeral expenses were a serious burden. A consistent and even more pronounced relationship is associated with the economic status the respondents. Clearly poorer parents suffered more as a result the expenses involved in having an adult child die from AIDS. Over two-fifths (43%) of poor parents reported the care and funeral expenses as a serious burden. This reaches over four-fifths of the cases in which a parent of poor economic status was a main contributor and had net funeral costs.

The results in table 21 clearly illustrate that both spending and adverse economic impact are related to economic status but in opposite directions. Lower economic status is associated with lesser amounts spent as a result of the illness and death of the adult child but with higher percents who reported that the costs were a serious burden for them. Apparently, even if expenses were not large in absolute amounts for poor parents, they were still more likely be severely taxing relative to their resources.

Opportunity costs. Besides direct expenditures, caregiving and making funeral arrangements may require parents to divert time from income generating or other activities of economic value. Table 22 addresses these potential opportunity costs. In almost half of the cases (47%) one or both parents had to either stop or reduce their economic activities. Curtailment of economic activity was over twice as likely for cases in which a parent was a main caregiver than in those in which a parent was not. Also the lower the economic status of the parents, the higher the percentage reducing their work.

Among married couples, both parents curtailed economic activities in about one-fourth of the cases and in about the same proportion of cases only one parent did. Under the latter circumstances, the mother was more commonly the person to divert time from economic activities than was the father reflecting the far greater tendency for mother to be main caregivers.

In general, the amount of time in which economic activity was curtailed was relatively short with the median duration being only one month. The distribution of time taken away from economic activities, however, is skewed and thus the mean duration (about three months) is considerably longer. Approximately a third of those who stopped or reduced their work, did so three months or more. In general, in situations where a parent was a main personal caregiver, the amount of time taken away from economic activities was longer than when no parent served as a main caregiver. In contrast, the duration of time taken away from normal economic activities does not vary greatly according to economic status.

Respondents were asked to estimate the amount of work on income that resulted from curtailing economic activity. In comparison to the amount spent for care and funerals, forgone income is considerably more modest. However, forgone income is substantially more among cases in which a parent served as a main personal caregiver than when a parent did not. Poorer parents indicated the value of time they lost to be less than among those of better economic status, probably reflecting the lower wages and income of those in lower economic status category.

If one or both spouses had curtailed their economic activity, respondents were asked if this had created financial hardship for their household. Overall just under a fifth (19 percent) said it caused little or no hardship while the remainder are more or less divided evenly between those who felt it cause some and those who thought it created lot of hardship. Cases in which a parent was a main personal caregiver were if anything less likely to say the curtailment of economic activity created hardship. Being of lower economic status, however, clearly increased the extent to which reduced economic activity caused a financial strain on the household.

Table 22 Curtailment of economic activities by parents of adult children who died of AIDS, by parents' role in caregiving and contributing to care expenses and economic status

	All cases	Was parent a main personal caregiver?		Economic status		
		No	Yes	Better off	Aver-age	Poorer
N of cases	394	113	281	75	131	187
% of cases in which a parent curtailed economic activity	47.0	23.9	56.2	41.3	46.6	49.2
Among married couples, percent in which:						
only father curtailed economic activity	7.1	3.6	8.0	7.1	8.8	5.6
only mother curtailed economic activity	17.3	12.5	18.6	12.5	16.5	20.6
both parents curtailed economic activity	24.3	8.9	28.6	23.2	22.0	26.2
Duration of work curtailment among those who curtailed economic activity (a)						
mean duration (in months)	3.1	2.3	3.2	3.4	3.2	2.9
median duration (in months)	1.0	1.0	1.0	1.0	2.0	1.0
% stopping 3 months or more	32.6	19.2	34.8	29.0	44.1	26.7
Among those who curtailed economic activity:						
Amount of forgone income (b)						
mean (in Baht)	8604	4332	9370	11318	8836	7595
median (in Baht)	2500	2500	2800	6750	2500	2500
% forgoing 5000+ Baht	41.4	22.2	44.9	60.7	38.6	36.4
Extent to which curtailment of economic activity created a financial hardship (% distribution)						
a lot	35.5	38.5	35.0	22.6	26.2	45.6
some	36.1	42.3	35.0	22.6	39.3	38.9
a little or not at all	28.4	19.2	29.9	54.8	34.4	15.6
total percent	100	100	100	100	100	100

Notes: (a) In cases where both parents curtailed their economic activity, duration refers to the longer period if the periods were unequal..

(b) In cases where both parents curtailed their economic activity, the forgone income refers to the combined income forgone by both parents.

Table 23 Selected means by which parents raised money to pay for care and funeral expenses of adult children who died of AIDS, by parents' role in contributing to care expenses and economic status

	All cases	Was parent a main contributor to expenses?		Economic status		
		No	Yes	Better off	Average	Poorer
N of cases	394	146	244	75	131	187
Taking on extra work						
% of cases in which a parent engaged in extra work to pay for care of funeral expenses	14.2	6.2	18.9	6.7	13.0	18.2
Of those who took on extra work, % still in engaged	66.1	**	67.4	**	76.5	64.7
Among married couples, percent in which:						
only father took on extra work	8.2	5.7	9.3	5.4	6.6	11.2
only mother took on extra work	2.4	1.4	2.7	0.0	1.1	4.7
both parents took on extra work	7.8	2.9	9.3	3.6	7.7	10.3
Borrowing money for care or funeral expenses						
% of cases in which a parent borrowed money	38.6	24.0	48.0	30.7	37.4	42.8
Among parents who borrowed:						
Amount borrowed (in Baht)	27103	22014	28638	44391	28898	20956
mean	15000	15000	15000	30000	20000	10000
median	32.9	20.0	36.8	34.8	26.5	36.3
% still in debt						
Sale of property and possessions to pay for care or funeral expenses						
% of cases in which a parent sold property or possessions	20.1	10.3	26.2	16.0	20.6	21.4
Amount received for sold property or possessions	154721	88127	168913	264882	268550	41982
mean	10000	7000	11300	24000	14000	10000
median						

** = less than 10 cases.

Means of meeting expenses. Given the substantial amount of costs involved with care, treatment and funerals, not all AIDS parents can cover these expenses from cash in hand or their savings. Table 23 addresses some of the ways in which parents raised money to pay for the costs involved in the illness and death of an adult child with AIDS. Results are presented both according to whether or not a parent was a main contributor to expenses and their economic status. In a small proportion of cases (14%), a parent took on extra work in order to pay for care or funeral expenses. This was more common in cases where a parent was a main contributor to the expenses and inversely related to economic status. Among those who did take on work, approximately two-thirds were still engaged in this extra work. In cases of married couples, fathers were more likely to take on extra work than mothers although in a substantial share of the married couples in which extra work was taken on both parents were involved. This pattern was similar whether or not a parent was a main contributor to expenses and varied little with economic status.

A more common means of meeting expenses than taking on additional work was borrowing money. In almost two-fifths (39%) of the cases a parent borrowed money for this purpose. In cases in which a parent was a main contributor to the expenses, borrowing money was twice as likely as in cases where the parent was not a main contributor. Economic status is inversely related to the portion who went into debt. Among parents who did borrow money, the amount borrowed was substantial. Those who borrowed had above average expenses and the amount borrowed was just over two-fifths of their combined care, treatment and funeral expenses (results not shown in table). The amount borrowed was greater when parents were main contributors to care and treatment expenses than when they were not. Although poorer parents were more likely to borrow, they borrowed substantially lower amounts on average than economically better off parents who borrowed.

In only about a third of cases of parents who borrowed to meet expenses the debt had not yet to be fully paid off by the time of the survey. It was far more common for those who were main contributors to expenses not to have paid off the loan than for those who were not main contributors. Economic status, however, shows no consistent association with the percent who were still in debt at the time of the survey.

Another way in which parents could meet expenses associated with an adult child with AIDS is to sell possessions or property. In about a fifth of the cases, parents reported that they sold property or possessions to pay for the care or funeral expenses. This was more likely to occur when a parent was a main caregiver. Also the percentages who did so are inversely associated with economic status. Poorer parents were most likely to sell something to meet expenses while better off parents were the least likely ones to do so.

The amount of money received for the property or possessions that were sold was substantial. Those who sold property or possessions, however, also had combined care and funeral expenses that were almost twice that of those who did not. Even so, the amounts received (as measured by the mean) exceeded the total costs (results not shown in table). Parents who were main contributors to expenses sold property and possessions of greater value than those who were not. Based on either means or the medians, the amounts received were lowest for parents who were poor. Median values also indicate parents of better off economic status received more than those of average economic circumstances but the means show little difference between these two groups of parents.

Assistance from family members. The burden of meeting expenses associated with the illness and death of an adult child with AIDS does not necessarily fall only on the parents, even when parents are main contributors. Qualitative analysis of in-depth interviews with AIDS parents indicate that other family members often joined together with parents to help meet the expenses involved (Saengtienchai and Knodel 2001). Table 24 indicates the percent of different family members and other persons who contributed to the payment of care and treatment expenses in relation to the role played by the parent. The survey did not include a question of who paid for the funeral besides the parents so the following discussion does not take funeral expenses into account.

Overall, in over half (53%) of the cases in which a parent was a main contributor to care and treatment expenses, others also shared the expenses. Whether or not a parent was a main contributor to the care and treatment expenses, siblings of the deceased adult child (i.e. other children of the AIDS parents) stand out as being particularly important in helping with expenses. Among siblings, sisters contributed to expenses more commonly than brothers. The adult child who died also contributed to his or her own expenses. In over two-fifths (41%) of the cases where a parent was not a main contributor, the deceased child helped pay for expenses and was the main contributor in over a third (36%). Spouses of the deceased adult child also made contributions to expenses in a number of cases. Among cases of deceased adult children who were currently married at the time of death, spouses helped in almost half of the cases when a parent was not a main contributor to expenses and in almost a third when the parents was a main contributor (results not shown in table).

Formal channels of assistance. Besides assistance from other family members and acquaintances, there are several important formal channels through which assistance with the expenses associated with AIDS are available in Thailand. As noted in the discussion of the Thai setting above, inexpensive or free health insurance is widely available through the government. In addition, several welfare programs exist that are targeted particularly to persons with AIDS and their families. Moreover, there are numerous NGOs that have programs designed to assist persons with AIDS although the

actual numbers of cases reached by these programs are far less widespread then those of the government (Im-em and Suwannarat 2002).

Table 24 Percent contributing to payment of treatment and care expenses, by relation to person who died of AIDS and parents' role in covering expenses

Relation to person who died of AIDS	Parent was not main contributor (a)		Parent was main contributor
	% making any contribution	% making a main contribution	% making any contribution
Self	41.1	35.6	17.6
Spouse	24.0	17.8	13.1
Parent	52.7	0.0	100.0
Any child	0.0	0.0	0.0
Any sibling	54.8	43.2	28.7
Brother	32.2	16.4	13.5
Sister	42.5	32.2	24.2
Other male	4.8	3.4	2.5
Other female	2.7	1.4	1.6
Other, sex unspecified(b)	8.9	5.5	3.3
% of cases in which persons other than a parent contributed	100.0	100.0	52.9
N of cases	150	150	240

Notes: (a) includes cases in which parents did not contribute to paying expenses
(b) Includes place of employment, NGOs, etc.

Table 25 indicates the extent to which health insurance and welfare assistance was received by adult children with AIDS or their families. Results are shown both in relation to whether a parent was a main contributor to expenses and to economic status of the parents. In approximately three-fifths of all cases covered by our survey, some form of health insurance helped pay for the medical costs of the adult child who died of AIDS. This was slightly more common in the cases where a parent was a main contributor to expenses than when a parent was not. Also health insurance was somewhat less likely to cover any medical costs when the parents were better off than if they were of average or poor economic status.

Table 25 Health insurance and welfare assistance received by adult children who died of AIDS and their families, by parents' role in contributing to care expenses and economic status

	All cases	Was parent a main contributor to expenses?		Economic status		
		No	Yes	Better off	Aver-age	Poorer
N of cases	394	144	242	75	131	187
Heath insurance						
% of cases in which health insurance helped paid for medical costs	59.6	55.6	61.6	50.7	62.0	62.0
Among cases for whom insurance helped pay medical expenses:						
Type of insurance used (% distribution)						
government health card (purchased)	50.4	41.3	55.7	47.4	60.0	44.7
welfare card	22.0	28.8	18.1	7.9	15.0	31.6
civil service/social security system	12.9	12.5	12.8	34.2	10.0	7.9
private	0.9	1.3	0.7	0.0	1.3	0.9
other	13.8	16.3	12.8	10.5	13.8	14.9
total percent	100	100	100	100	100	100
Extent to which insurance helped with expenses (% distribution)						
very much	55.7	60.3	52.4	48.6	52.6	60.2
some	34.6	30.8	37.4	37.8	41.0	29.2
not much	9.6	9.0	10.2	13.5	6.4	10.6
total percent	100	100	100	100	100	100
AIDS Welfare assistance (a)						
% of cases that received welfare payments	18.8	15.4	20.7	14.9	14.0	23.9
Among cases who received welfare:						
Duration of payments (% distribution)						
1 month or less	41.2	30.0	46.8	**	44.4	33.3
2-5 months	17.6	20.0	14.9	**	5.6	21.4
6+ months	20.6	20.0	21.3	**	38.9	16.7
family still receives payments	20.6	30.0	17.0	**	11.1	28.6
total percent	100	100	100	**	100	100
Amount received						
mean	10342	13704	9095	3818	22416	7189
median	4000	4500	4000	4000	6000	3850
Extent to which welfare helped with expenses (% distribution)						
very much	19.1	11.1	22.4	9.1	13.3	23.8
some	35.3	44.4	30.6	9.1	60.0	33.3
not much	45.6	44.4	46.9	81.8	26.7	42.9
total percent	100	100	100	100	100	100

Notes: (a) Welfare payments include assistance from NGOs.

** = less than 10 cases.

The vast majority of cases in which insurance helped pay medical expenses involved some government program. Almost none of the cases had private health insurance. By far the most common was the voluntary government health card scheme in which membership can be purchased for a modest amount by families not covered by other programs. In addition, a substantial share were covered through a welfare card directed towards those with particularly limited resources of their own. Civil service benefits and the social security system also accounted for a minority of the medical payments. The percentage of cases in which medical expenses were paid at least in part through a welfare card is inversely related to the economic status of the parents while the reverse is true for the percentage receiving coverage through civil service or social security benefits.

Responses to a question about the extent to which the health insurance helped with expenses, indicate clearly that these schemes were of considerable assistance. Only 10 percent of the cases for which health insurance was used indicated it was of little help. In contrast, more than half (56%) of those who received some coverage through insurance indicated that it helped a great deal and over a third said it helped at least some. The percent who indicated the insurance helped a great deal is inversely related to the economic status of the parents although even among the better off parents, the insurance appears to have been of substantial help in almost half of the cases.

A considerably smaller share of cases received some sort of AIDS welfare assistance (including help from NGOs). These payments typically were often made to the person who was ill with AIDS and thus not directly to the parents. Nevertheless, the parents as a common contributor to expenses presumably benefited from such payments in many such cases. This was substantially higher among cases in which the parents were poor than among other cases. It was also somewhat higher for cases in which a parent was a main contributor to care and treatment expenses.

In general the period during which welfare was provided was often rather short. In over two-fifths of the cases, payments were received only during a period of one month or less (some being one time assistance). About the same proportion of cases, however, either reported receiving welfare for six months or longer or reported that the family still received some welfare payment. Cases in which parents were poor also seem to receive welfare somewhat longer than others.

The amount received as welfare payments are relatively modest compared to typical total expenses involved in care, treatment and funerals. Even though the combined costs of care and funerals were considerably less than average for those who received welfare (as judged by the means), the amount received by welfare averaged only about a third of the costs reported (results not shown in table). This may explain why, in

cases in which welfare was received, the most common response concerning the extent it helped with expenses was that it did not help much. Only about a fifth (19%) said that the welfare payments helped very much. This percentage, however, was higher for those in which parent was a main contributor to expenses and is inversely related to the economic status of the parents.

Longer Term Economic Impacts

Parents who contribute to the costs of caregiving, treatment and funerals may experience financial strain during the period of illness and shortly after the death of their son or daughter with AIDS. In cases where these expenses lead to serious depletion of savings, debt or sale of property or possessions, longer term repercussions could also result. For those who spent within their means, however, when these expenses end, any economic hardship associated with them would also dissipate. In contrast, AIDS parents who take responsibility for expenses associated with surviving dependents of their deceased son or daughter typically continue to incur costs well beyond the death. In addition, longer term economic consequences for parents could result from the loss of any current support that the deceased adult child had been providing or from loss of future anticipated support that might have been provided in later years of life. We asked a series of questions in our survey to AIDS parents designed to directly assess assistance with expenses for dependents and loss of filial support. In addition, comparisons of information collected for both AIDS and non-AIDS parents provides an additional basis for inferring some of these longer terms consequences.

Costs for dependents. The primary involvement of AIDS parents with dependents is in association with grandchildren orphaned by the death of their adult son or daughter. Occasionally AIDS parents might also assist the spouse of the deceased child. According to our survey, as table 26 shows, in almost a third of the cases AIDS parents had assisted a dependent of their deceased child. As noted earlier, a substantial proportion of the adult children who died either were never married or had no children. In over half of the cases in which the deceased son or daughter had children of their own, a parent helped pay expenses for dependents (presumably involving expenses mainly for the grandchildren). Even when the deceased son or daughter had only a surviving spouse and no children, the parent helped support the surviving spouse at some point in almost a third of the cases. In many cases this help was probably limited to the period of caregiving when the spouse and ill son or daughter were living with the respondent.[20]

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[20] This is suggested by the following evidence. We asked respondents who had covered expenses to dependents prior to the time of the survey, if they expected to continue such support. In most cases in which the deceased adult child had a spouse but no children, the respondents say they did not expect to be continuing covering expenses. In contrast, in cases where the deceased n or daughter had child, a majority said they did expect to continue support (results not shown in table).

Table 26 Parental involvement in expenses related to dependents of adult children who died of AIDS

	All cases	Cases in which the adult child who died	
		had surviving spouse but no children	had children
N of cases	394	43	193
% of cases for whom a parent helped pay expenses for a dependent	31.5	30.2	57.0
% of cases for whom a parent helped pay for:			
medicine	18.8	4.7	37.3
transportation	19.8	11.6	38.0
food	31.0	30.2	56.3
clothing	23.5	4.8	46.9
school expenses	16.1	n.a.	32.8

The most common source of expenses for AIDS parents in connection with dependents of the deceased child was food. In cases where no grandchildren were involved, it was relatively uncommon for the AIDS parents to incur other types of expenses for the spouse. When grandchildren were involved, expenses for a whole array of items were relatively common. In about a third of such cases the AIDS parents indicate they paid for school expenses. Since some of these children have yet to enter school, however, it is quite possible that expenses for school in the future will be covered by some AIDS parents who have yet to do so. More broadly, as noted above, some of the AIDS parents whose grandchildren who are currently being cared by the surviving spouse of their deceased son or daughter will eventually inherit responsibility for the grandchildren, especially in cases where the surviving spouse is HIV infected and thus will die before long. This will also result in future expenses to the AIDS parents that are not yet evident at the time of our survey.

Loss of filial support. From a longer term perspective, the potentially most serious economic impact for some AIDS parents is the loss of the current and future support that the deceased would have provided. If the deceased son or daughter had been contributing to the parents' household income, and especially if the adult child was a main contributor, the loss of income could lead to a sustained long term reduction in economic well-being. As table 27 shows, in over 70 percent of the parental households covered by our survey, the deceased child provided some material assistance to the

Table 27 Contribution of adult child who died of AIDS to parental household

	All cases	Economic status		
		Better off	Average	Poorer
N of cases	394	75	131	187
Contribution of the deceased adult child to parental household income during year prior to serious illness (% distribution)				
main provider	32.4	17.3	26.0	43.2
some but not over half	15.6	17.3	13.7	16.2
only a little or other	23.2	29.3	26.0	18.9
none	28.8	36.0	34.4	21.6
total percent	100	100	100	100
Amount of income provided during year prior to serious illness				
Among deceased children who contributed any income				
mean	13341	20280	11323	12415
median	6000	12000	5700	4750
Among deceased children who were main providers				
mean	16316	22460	15058	15951
median	10400	12000	11400	10000
Coresidence and household services				
% of deceased adult children who were coresident with a parent before becoming seriously ill				
continuously	57.6	58.7	61.8	54.0
part of time	16.0	12.0	14.5	18.7
Among coresident deceased adult children, extent of help they provided with household chores or family economic activities (% distribution)				
regularly	47.9	43.4	44.0	52.2
irregularly	29.0	43.4	25.0	26.5
% of parental households in which someone moved in to help with support and maintenance since adult child with AIDS became ill and died:				
among all parental households	5.8	4.0	7.6	5.3
among parental households in which deceased child was continuously coresident before illness	7.5	4.5	8.6	7.9
Extent to which loss of income or services provided by the deceased child makes financial situation difficult (% distribution)				
much more difficult	27.4	8.2	15.0	44.0
somewhat more difficult	26.1	28.8	25.2	25.7
not at all	23.7	35.6	32.3	12.6
child did not contribute	22.9	27.4	27.6	17.7
total percent	100	100	100	100

parents during the year prior to becoming seriously ill and in almost a third had been the main income provider. These overall proportions are likely inflated somewhat by the skewed nature of our sample as discussed above. Particularly noteworthy is the strong inverse association between the parents' economic status and the loss of a child who was a main income provider. Deceased children of poorer parents were more than twice as likely to have been the main income earner than those of better off parents, most likely reflecting a greater need for such support among poor older persons.

The amount of income provided by the deceased child during the year prior to being ill among those who contributed income to the parental household was fairly substantial in relation to average per capita income in Thailand. This is particularly true among deceased children who were main providers for the household. The contributions to the parental household of better off economic status were greater in absolute amounts than to those of lower economic status based on the mean amount provided. However among cases where the deceased child was a main provider, there is little relationship between the economic status of the parents and median amount of monetary support received.

Adult children can also provide important services to their older age parents, particularly if they coreside with them. As table 27 indicates, regardless of economic status, over half of the deceased children were coresident with the parent prior to serious illness and an additional share lived with the parents at least part of the year or intermittently spent time living in the parental home. These proportions are quite high reflecting the skewed nature of our sample as discussed above. In most cases where the deceased adult children had been coresident, they had been of at least some assistance providing help with household chores or with family economic activities. Almost half (48%) of the coresident children had provided regular assistance. The extent to which regular assistance had been provided by deceased coresident children is particularly high among parents who were poor.

In order to assess if living arrangements were adjusted to make up for the loss of a coresident adult child, we asked respondents if someone else moved into the household following the illness and death of their adult child with AIDS to assist with support and maintenance of the household. Only a minority of respondents reported anyone moved in. Even when conditioned on those parental households in which the deceased child was continuously coresident before the illness, only eight percent of respondents reported someone else augmenting the household. There appears to be little relationship between economic status and someone else moving in response to the loss of the child who died with AIDS.

We directly asked AIDS parents to assess the extent to which the loss of income or services provided by the deceased child created difficulties for their financial situation. Over half of the respondents reported that the situation was either much more or somewhat more difficult. The proportion reporting that the situation was much more difficult shows a pronounced inverse association with their economic status. Only a small minority (8%) of economically better off respondents reported that the loss of the income or services provided by the deceased child created serious difficulty compared to 44 percent of those who were poor.

Comparisons with non-AIDS parents. As mentioned in the description of the survey design, most of the deaths of the adult children from AIDS occurred between six months and three years prior to the survey. Thus comparisons between AIDS parents and those who had not experienced any recent adult child death with respect to their economic circumstances, and particularly changes in those circumstances over the prior three years, should reflect any sustained intermediate-term economic impact of the loss of a child to AIDS. Table 28 presents the relevant comparisons.

AIDS parents were more likely than the comparison group to judge their current financial status as difficult and less likely to indicate it as comfortable. This could reflect pre-existing differences between two groups given that the AIDS parents appear to be from somewhat more disadvantaged backgrounds (see table 3 and associated discussion). However, AIDS parents were also more likely to indicate that their financial status had become much worse over the past three years thus providing more convincing evidence that the loss of an adult child to AIDS had a detrimental effect on their economic situation. Nevertheless, when AIDS parents were asked an open-ended question as to why their financial status worsened, less than a third specifically mentioned the costs of the child's illness as the main reason. Note that the period covered coincided with the economic downturn in Thailand associated with the Asian economic crisis of recent years. This may account for why substantial proportions of non-AIDS parents also reported that their financial status worsened.

AIDS parents were also more likely than non-AIDS parents to indicate that they were currently experiencing debt, that their current debt was serious, that they were in debt three years prior to the interview, and that the debt at that time was serious. In response to an open-ended question, approximately a fifth of the AIDS parents who said their debt was serious indicated that their child's illness the reason for their debt, both with respect to the current debt and the earlier debt.

Table 28 Financial status and indebtedness of AIDS and non-AIDS parents

	AIDS parents households	Non-AIDS parents households
Financial status		
Current financial status (% distribution)		
Comfortable	12.7	20.8
Neither comfortable nor difficult	30.2	38.4
Difficult	57.1	40.8
Total	100	100
Change in financial status over past 3 years (% distribution)		
the same or better	46.4	53.7
somewhat worse	34.0	35.9
much worse	19.5	10.4
total	100	100
Among those whose financial status worsened, % who give costs of child' illness/death as a reason	28.4	--
Indebtedness		
% with any debt		
currently	43.4	39.6
3 years earlier	44.5	37.6
% with somewhat or very serious debt		
currently	33.8	26.8
3 years earlier	30.5	24.0
Mean debt (in 1000s of Baht)		
Currently	104.2	116.0
3 years earlier	155.3	142.8
% who give costs of child' illness/death as a reason among those with serious debt		
currently	19.6	--
3 years earlier,	18.3	--

As noted in the section on the Thai setting, many older-age parents depend on adult children for at least some of their economic support and that this familial system of support for older parents is closely linked to coresidence with or living nearby an adult child. Table 29 presents comparisons between AIDS and non-AIDS parents with respect to living arrangements, several aspects of household composition, and support from household members and adult children in general.

Table 29 Living arrangements and household composition, support from household members and support exchanges with children, AIDS and non-AIDS parents

	AIDS parents households	Non-AIDS parents households
Living arrangements and household composition		
% of households with	65.0	72.9
a coresident adult child		
with a minor (under 15) in household	56.6	48.7
with a foster child in household (a)	31.5	12.8
with a double-orphaned child in household (b)	11.7	0.3
Location of nearest adult child (% distribution)		
same house	63.7	72.1
next door/ nearby	13.2	11.4
same locality	3.0	4.5
same district	5.1	4.8
same province	5.1	2.7
elsewhere	7.4	4.5
no adult child	2.5	0.0
total	100	100
Support from household members		
Mean number of members employed last year	2.3	2.5
Mean number of members who contribute to support.	2.3	2.4
Support exchanges with children		
% of respondents who received from at least one adult child during previous year:	67.8	72.3
1000+ Baht in cash	61.2	69.9
material gifts worth 1000+ Baht		
% of respondents who gave to at least one adult child during previous year:	36.8	45.5
1000+ Baht in cash	27.9	36.2
material gifts worth 1000+ Baht		
Change in support from children		
% who receive less support from children now than 3 years ago	41.9	25.9
Among those receiving less support from children currently than 3 years earlier, % who give child' illness/death as a reason	47.3	--

Notes: (a) a foster child is a child under age 15 whose parents do no live in the same household.
(b) A double-orphaned child is one whose both parents are dead.

AIDS parents were somewhat less likely than non-AIDS parents to be coresident with an adult child at the time of the survey. Nevertheless, an adult child was present in approximately two-thirds of the AIDS parents households. In contrast, AIDS parents households were somewhat more likely to contain a minor aged member and distinctly more likely to contain a foster child (i.e. whose parents are not present even if alive) or a double-orphaned child (i.e. whose both parents are deceased). Although there is little difference between AIDS and non-AIDS parents with respect to having a child live nearby or in the same locality, AIDS parents are somewhat more likely to have the nearest child live at some distance. Rarely did the death of their son or daughter leave AIDS parents with no living children.

The average number of household members who were employed during the prior year and who contributed to the support of the household is only slightly less for households of AIDS parents than those of non-AIDS parents. A more pronounced difference is evident with respect to support from children in general (including those living outside the household). AIDS parents were less likely than non-AIDS parents to have received significant cash, defined as 1000 Baht or more, from an adult child during the previous year or to have received material gifts worth an equivalent amount. At the same time, AIDS parents were also less likely themselves to have provided significant cash or material gifts to their children. A substantially higher proportion of AIDS parents indicated that they received less support from their children now than three years ago and that half of the AIDS parents whose support was reduced stated the reason was the death of their child.

Overall the results comparing AIDS and non-AIDS parents suggest that some parents experience serious negative economic consequences associated with the loss of the child to AIDS. It also appears, however, that this is so for only a modest minority of the cases.

Community Reaction

AIDS is a stigmatized disease throughout much of the world although the nature, degree, and consequences of stigma are likely to vary considerably across settings and over time (Leary and Schreindorfer 1998); (Malcolm et al. 1998). Stigma may extend beyond the infected persons to those closely associated with them, especially those who are providing personal care (Brabant 1994; Powell-Cope and Brown 1992). Some main manifestations include negative attitudes towards and disassociation with those who are stigmatized and thus can undermine their social activities and contacts. Stigma associated with AIDS may also prevent the infected person and their family caregivers from asking others for assistance or seeking services from health or social service providers (Ory, Zablotsky, and Crystal 1998). Our survey results suggest that in Thailand by the late

1990s, most community reaction experienced by AIDS parents was relatively sympathetic to their situation although negative experiences continue to affect some.

Community members must be aware that the son or daughter of the AIDS parents has been ill if they are to react to the situation. Thus we first asked if others knew of the illness before asking about community reactions. In line with our strategy to avoid explicitly referring to AIDS, however, we did not ask if those in the community who knew about the illness believed it was related to AIDS. In 95 percent of the cases, at least some community members were aware that the adult child of the AIDS parents was ill prior to the death. For the small number of remaining cases who said others in the community were unaware of their child being ill, we skipped community reaction questions related to the period of illness in the interview. Moreover, our questions were oriented to address community reaction to the parents or to situations that included the parents rather than reactions directed only at person with AIDS (see section H of the questionnaire in the appendix).

Table 30 provides an overview of the reaction of neighbors and other community members to the respondent and his or her spouse both during the period when the adult child was ill and after the child's death as reported by AIDS parents. Fully two thirds of respondents reported that others only reacted in a positive manner during the time their adult child was ill and three-fourths said the reactions following the child's death were only positive. This differs little according to whether or not a parents was a main caregiver. Moreover among those who reported experiences with negative reaction, most indicated that their experience was of a mixed nature. Only a relatively small minority said the reaction was solely or mainly negative.

Another indication that the extent of negative community reaction is limited is provided by reports about attendance at the deceased child's funeral. There is little evidence that community members commonly avoided the funeral of deceased adult child. Less than 10 percent of respondents indicated that attendance at the funeral of their child was below normal. This percentage shows little relations to whether or not parent was a main caregiver.

Among the minority of AIDS parents who experienced negative reaction, approximately a third indicated the duration of negative reaction during the period of illness was less than a month. An even higher proportion (45%) indicated that the negative reaction after the child's death lasted less than a month. Just under a fifth (19%) of respondents, however, said the negative reaction from the period of illness was still ongoing and just over a quarter (26%) indicated that the negative reactions following the death of the child were still occurring. In very few cases, however, was the negative reaction so strong that parents considered moving out of the community because of it. In

general, the duration of negative reaction seems unrelated to the role of parents as main caregivers. However considering moving out of the community during the period of illness is higher in cases in which a parent was a main caregiver.

Table 30 Overview of community reaction to AIDS parents during the illness and after the death of their adult child, by caregiving status

	During the illness			After the death		
	All cases	Was a parent a main caregiver?		All cases	Was a parent a main caregiver?	
		No	Yes		No	Yes
Type of reaction (percent distribution						
only positive	67.6	68.2	67.4	74.7	76.6	73.9
some negative but mostly positive	14.2	12.7	14.9	11.5	7.2	13.2
mostly/only negative	7.3	4.5	8.3	4.2	1.8	5.1
neutral/other	10.9	14.5	9.4	9.7	14.4	7.7
total percent	100	100	100	100	100	100
% reporting funeral attendance was below normal	n.a	n.a	n.a	8.4	9.7	7.9
Among those experiencing negative reaction:						
Duration of negative reaction (percent distribution)						
less than a month and then ended	32.6	38.9	31.2	44.9	40.0	45.8
more than a month and then ended	48.4	44.4	49.4	29.0	40.0	27.1
ongoing	18.9	16.7	19.5	26.1	20.0	27.1
total percent	100	100	100	100	100	100
% who thought of moving away because of negative reaction (a)	12.5	5.3	14.3	n.a	n.a	n.a

Note: (a) Question asked only in relation to negative reaction during [period of illness.

Our questionnaire also included questions about specific types of community reactions. Respondents were first asked about specific reactions in an open-ended manner. They were then probed about any they did not mention spontaneously. Table 31 presents the results. When asked more specifically about positive reactions during the time of illness, the vast majority (95%) of respondents said that other community members visited them and almost two thirds said some brought food. More than a third reported that friends and neighbors helped in looking after their ill adult child (36%) and helped with providing transportation or joining them to the hospital (38%). In contrast, slightly less than a fourth of respondents reported that others gossiped about them, only a

fifth said some in the community avoided visiting during the period of the illness, and even fewer said that some avoided talking with them. When asked about specific reactions their adult child died, 95 percent said community members helped with the funeral arrangements and almost 90 percent reported social visits. At the same time, only one in six reported gossip and less than 10 percent reported that some community members refused to attend the funeral, refused to eat at the funeral, or avoided social contact.

In general there is little difference in the frequency of specific positive community reactions according to the caregiving status of the parents. However cases in which a parent served as a main caregiver were consistently more likely to report each type of negative reaction suggesting that closer involvement with caregiving may cause some in the community to be concerned about the possibility of contagion from parents as a result of caregiving activities.

Some persons in community, by virtue of their position, are particularly important in influencing access to health care or welfare assistance to a person with AIDS and their families. For example, in some government health insurance plans free access to higher level units in health system requires referral by the lowest level unit (typically then local heath center). Likewise, receipt of welfare payments sometimes requires approval by a local committee over which the village headman presides. Our survey asked respondents specifically if local health staff, village health volunteers and the village headman showed any negative reactions.

As results in table 32 show, slightly over half (53%) of the respondents indicated that health-care staff had been helpful and approximately two-thirds indicated that community health volunteers and the village headman (or urban community leader) had been helpful. Very few reported negative reactions from any of these sources. In addition, there is little difference between cases in which a parent was a main caregiver and those in which a parent was not in these respects.

It is possible our results somewhat understate negative community reaction. A few AIDS parents mentioned that others in the community did not know of their child's illness or that their neighbors did not react one way or the other. Both of these situations may reflect efforts on the parents part to prevent knowledge of their child's illness from spreading because they anticipated negative reactions. Also AIDS parents who had particularly bad experiences may have been unwilling to be interviewed. Still the overall picture seems clear. Most parents of persons with AIDS find sympathy and support from their friends and neighbors and only a minority suffer substantial negative reactions as a result of losing a child to AIDS. There is some evidence, however, that suggests that

while close involvement in caregiving does not reduce the chances of positive social support it may increase the chance of encountering negative reactions.

Table 31 Percent experiencing specific reactions from other community during the period of illness and after the death of their adult child, by caregiving status

	All cases		Was a parent a main caregiver (prompted plus unprompted)	
	Unprompted only	Total	No	Yes
% reporting specific reaction of other community members during period of illness				
Positive reactions				
visited	80.2	95.7	96.1	95.6
looked after your sick child	12.6	35.7	38.8	34.4
brought some food	21.9	63.4	65.0	62.7
brought some medicine	5.1	27.6	29.1	27.0
gave advice (e.g., about food, care and medicine)	11.5	61.4	67.6	59.0
provided transportation or joined when going to hospital	4.6	38.0	39.8	37.3
Negative reactions				
avoided talking to you or others in household	4.4	14.0	7.2	16.4
gossip	6.3	24.7	20.2	26.3
would not visit your home	7.3	20.4	17.9	21.3
% reporting specific reaction of other community members following death				
Positive reactions				
visited	49.7	90.0	91.9	89.2
helped with the funeral arrangements or activities	47.8	95.1	97.3	94.3
attended the funeral activities	47.8	98.0	98.2	97.8
Negative reactions				
avoided conversations you or others in your household	2.6	7.5	3.7	9.0
gossiped	3.8	15.7	9.0	18.4
would not visit your home	2.6	9.6	4.5	11.6
refused to attend the funeral (if local funeral)	1.0	8.4	3.6	10.3
refused to eat or drink at the funeral (if local funeral)	1.3	7.9	6.5	8.4

Table 32 Reactions of local health staff and community officials to adult child with AIDS and parents, by caregiving status

	All cases	Was a parent a main caregiver	
		No	Yes
Health center staff			
% helpful	52.9	55.2	51.9
% showed negative reactions	3.5	2.9	3.8
Community health volunteer			
% helpful	67.1	58.5	56.6
% showed negative reactions	3.5	3.7	3.4
Village headman			
% helpful	64.9	60.4	66.7
% showed negative reactions	4.2	2.8	4.8

Conclusions

The collection of systematic empirical data on the impact of the AIDS epidemic on older persons through the illness and death of an adult son or daughter poses serious challenges. Such data, however, are critical for making a realistic assessment of the problems and needs of older persons in their role as AIDS parents as well as to identify ways in which this group of persons, so intimately involved in the epidemic, can contribute to dealing with the many challenges it poses for the society of which they are part. While reliance on anecdotal evidence or cases studies can be suggestive of the situation and help identify relevant issues, they cannot ultimately substitute for broad based and systematic evidence of their dimensions and prevalence.

The present report has described the methodology and findings of a direct interview survey of parents of deceased adult children who died of AIDS and a comparison group of older age parents who had not suffered such a loss. The results provide extensive information on a wide range of potential impacts. Implementing such a survey, however, requires overcoming a number of logistical difficulties, the solutions to which can compromise the representativeness and accuracy of its findings. In our case, the use of local intermediaries to identify cases of AIDS and non-AIDS parents and to assist in recruiting them for interviews was a practical solution that overcame what probably were otherwise almost insurmountable barriers to carrying out such a survey. However this solution came with a cost, namely that our sample of AIDS parents is skewed towards those whose deceased child either lived with them or nearby during the terminal stage of the illness. Thus results are biased towards parents who were more

involved in the care and general situation of their ill sons and daughters. The results are less likely to be biased, however, with regards to the subset of AIDS parents who are directly involved in caregiving and living arrangements of their AIDS infected adult children. As other evidence from our project has established, this subset is very large and very likely constitutes a substantial majority of AIDS parents overall in Thailand.

The detailed results of our survey permitted examination of a wide range of potential effects on AIDS parents and show considerable diversity in the extent parents are impacted. Clearly personal caregiving and instrumental assistance by parents, especially the mother, can be very demanding and involve a wide range of tasks. At the same time, the duration of intensive caregiving usually lasts only a month or two. Even when a parents is a main caregiver, other family members, particularly siblings of the deceased, often assist the parental caregiver. Parents also often serve as critical links between their ill adult child and the health care system. They frequently accompany their infected son or daughter to health service outlets, stay with them in the hospitals, and consult with health care providers about appropriate treatment. Care giving also often takes a toll on the emotional and physical health of the parental caregiver at the time care is being provided. Longer term impacts on physical health at least do not appear to be common.

Only a minority of the AIDS parents fostered grandchildren left behind by their deceased son or daughter. One important reason for this was that for over half of the AIDS parents, the deceased son or daughter had no children. In circumstances where grandchildren did exist, however, it was fairly common for the grandparents to be involved in raising them.

Overall, the loss of a child to AIDS has a serious economic impact only for a minority of AIDS parents. Those parents who spent substantial amounts on treatment tended to be economically better off than average and hence could likely afford to do so without lasting financial hardship. At the same time, the poor appear to be the most adversely affected. Even though they spent less on treatment, caregiving, and funeral expenses, the amounts were more devastating for them relative to their economic resources. One implication of this finding is that interventions intended to help older-aged parents deal with the financial strains associated with losing an adult child to AIDS should take into account the considerable range of vulnerability that exists and target those who are particularly susceptible to resulting economic hardship.

Some potential impacts of losing an adult son or daughter to AIDS may not become apparent until long after the adult child's death. In particular, the full implications of the loss of a potential provider of care in old age or a contributor to material support may not become evident until the parents' health and physical stamina

decline resulting in frailty and a need to depend on others for material support. Our survey is likely to miss these potential long term effects because insufficient time had past at the time of data collection for them to manifest themselves. At the same time, most AIDS parents have other surviving children on whom they can depend, reflecting the high fertility levels that prevailed in Thailand until several decades ago. Thus for many the loss of just one son or daughter may not seriously jeopardize their old age care and support from adult children.

Sustained social stigma directed at parents of persons who died of AIDS is far from universal in Thailand at present. Sympathetic and supportive reactions from others in the community are more frequently reported than negative ones. Clearly negative reactions are not absent in many community settings. However, it may be that anecdotal evidence of extreme negative reaction, especially during early stages of the epidemic, has lead to an exaggerated and out-dated view of the predominance of stigmatization and to resistance to recognizing that community members can also be sympathetic and helpful to a family unfortunate enough to lose a member to AIDS.

One implication of the relative predominance of positive community reaction is that programs designed to build on community support in order to assist families with a member ill with AIDS or who have suffered an AIDS death would meet less resistance than might otherwise be thought. It also reduces what could potentially be an important barrier to home care by parents (Malcolm et al. 1998). A more accepting community attitude is likely to increase the willingness of an ill adult child to return home from elsewhere and that of the parents to accept responsibility for an AIDS inflicted son or daughter.

The particular culture, politics, and levels of socio-economic development of any setting as well as the dimensions and characteristics of the epidemic are likely to condition the nature and magnitude of its impact on older persons. Thailand shares important characteristics with many of countries with moderate to severe levels of the HIV/AIDS epidemic that are likely to condition the implications for parents and families. These include the heterosexual nature of most transmission and the dependence of parents on adult children for old age support. There are also features of the Thai situation, however, that distinguish it from many other developing countries, particularly those in Africa where the severity of the epidemic is far worse. Many of these features are likely to moderate the impact of the epidemic on older-aged Thai parents compared to parents in other settings where they are absent. These include a well developed public health system, reasonably widespread availability of government health insurance, an unusually successful effort to openly confront the epidemic and to educate the public about it, and low fertility among the generation of adults in the prime AIDS ages combined with high past fertility of their parents. Moreover, Thailand has it's own

particular cultural setting, strongly influenced by its heritage of Theravada Buddhism, within which the causes and consequences of epidemic play out. Thus while the findings of our survey are likely to have relevance in some respects for other developing countries with AIDS epidemics, they also need to be understood in terms specific to the Thai context.

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Appendix. Questionnaire for Survey of Impact of Adult Child Death on Parents

Questionnaire number: ____

Interviewer name _____

Date: _____

Sample site _____ Province _____ Amphur

_____ Tambol _____ Village

Type of respondent (based on listing from key informant):

1 Parent(s) with child who died of target disease

2 Parent(s) no child death (control case)

What kind of area is the respondent living in now?

1 Rural village

2 Sanitary district (sukapiban)

3 Provincial or district town

Time interview starts _____ Hour _____ Minute

Opening Statement:

A. *If target interview involves a death of an adult child:* Thank you for being willing to participate in our study. We want to assess the current living conditions of older persons in this community. We also want to try to understand what happens to parents if they are so unfortunate to experience the loss of an adult child. We were told that that you have lost a child recently.

[At this point clarify that the respondent lost a child.]

We would also like to ask you some questions about that. We know that this can be a very difficult issue for many people to talk about it, and you should tell us if you do not want to answer any question, or if you decide that you would rather not participate after all. Your participation is voluntary and the questionnaire is anonymous. We do not record your name anywhere on the form and all information you provide will be anonymous.

B. *If target interview does not involve a death of a an adult child:* Thank you for being willing to participate in our study. Our goal is to try to assess the current living conditions of older persons in this community. Your participation is voluntary and the questionnaire is anonymous. Please tell us if you do not wish to answer any question. We do not record your name anywhere on the form and all information you provide will be anonymous.

Determining respondent in case of couples : In cases of an older couple living together, one person needs to be treated as the 'respondent' and the other as the 'spouse'. If only one of the couple is present, then this person should serve as the respondent. If both are present, chose either the husband or wife as 'respondent' and treat the other as the spouse. Note the purpose of this selection is to have clear references for questions which differentiate between the respondent and spouse. In practice, both husband and wife may participate in answering the questions. The 'spouse' may even be more active in answering than the chosen 'respondent'. It does not matter which of the couple actually answers as long as the answers are recorded consistently in terms of who is treated as 'respondent' and who is treated as 'spouse'. In general, you should try to encourage both husband and wife to participate in the interview. If they disagree in an answer, record the response of the designated respondent but note the disagreement in the margins.

Before starting the interview, determine the marital status of the older person(s) targeted for interview and indicate below who is the respondent. When a couple is targeted for interview, chose a respondent as described above.

Check interview target:

__ man who is widowed, separated, divorced or living separately from wife (start interview)

__ woman who is widowed, separated, divorced or living separately from husband (start interview)

__ married couple living together (indicate respondent first and then start interview)

__ Wife is respondent

__ Husband is respondent

Are both husband and wife present at start of interview? ___ yes ___ no

A. Household Schedule

A1. We would like to know some information about everyone you live with here in your household . Let's start by listing everyone who regularly lives here starting with yourself .

List everyone who lives in the same household with the respondent before asking the detailed information about each one . Be sure to list the designated respondent as the first person and the spouse (if appropriate) as the second. If more than 12 household members, continue on a second questionnaire.

(a) Person no.	(b) Nick name or 1st initial	(c) Relation -ship to R	(d) Sex		(e) Age - probe year of birth	(if age 3 or older) Has (name) moved into HH in last 3 years?				(i) Highest grade of school finished	(j) If age 3-24		If age 16 or older							
						(f) Yes/no		if yes, how long ago			Is (name) still in school (include pre-school)		(k) Marital status				(l) Work last year (last 12 months)?		(m) Does (name) help support HH	
								(g) yrs	(h) mos				single	married	div/ sep	widowed				
			M	F		yes	no				yes	no					yes	no	yes	no
1		self	1	2		1	2				1	2	1	2	3	4	1	2	1	2
2			1	2		1	2				1	2	1	2	3	4	1	2	1	2
3			1	2		1	2				1	2	1	2	3	4	1	2	1	2
4			1	2		1	2				1	2	1	2	3	4	1	2	1	2
5			1	2		1	2				1	2	1	2	3	4	1	2	1	2
6			1	2		1	2				1	2	1	2	3	4	1	2	1	2
7			1	2		1	2				1	2	1	2	3	4	1	2	1	2
8			1	2		1	2				1	2	1	2	3	4	1	2	1	2
9			1	2		1	2				1	2	1	2	3	4	1	2	1	2
10			1	2		1	2				1	2	1	2	3	4	1	2	1	2
11			1	2		1	2				1	2	1	2	3	4	1	2	1	2
12			1	2		1	2				1	2	1	2	3	4	1	2	1	2

Person no.	If under age 15																	
	Where are parents of this child? 1=in HH 2=next door/nearby 3=elsewhere 4=dead		If one or both parents are dead, how long ago did parent die ?				If one or both parents of the child under 15 live elsewhere											
	(n) Mother	(o) Father	(p) Mother		(q) Father		(r) Do parent (s) help support child?		(s) If yes to (r), about what share of the expenses for child do parents cover				(t) Do you help support child?		(u) If yes to (t),about how much of the expenses for child do you cover?			
			yr	mo	yr	mo	yes	no	all or most	half or more but not all	less than half	little or none	yes	no	all or most	half or more but not all	less than half	little or none
1	1 2 3 4	1 2 3 4					1	2	1	2	3	4	1	2	1	2	3	4
2	1 2 3 4	1 2 3 4					1	2	1	2	3	4	1	2	1	2	3	4
3	1 2 3 4	1 2 3 4					1	2	1	2	3	4	1	2	1	2	3	4
4	1 2 3 4	1 2 3 4					1	2	1	2	3	4	1	2	1	2	3	4
5	1 2 3 4	1 2 3 4					1	2	1	2	3	4	1	2	1	2	3	4
6	1 2 3 4	1 2 3 4					1	2	1	2	3	4	1	2	1	2	3	4
7	1 2 3 4	1 2 3 4					1	2	1	2	3	4	1	2	1	2	3	4
8	1 2 3 4	1 2 3 4					1	2	1	2	3	4	1	2	1	2	3	4
9	1 2 3 4	1 2 3 4					1	2	1	2	3	4	1	2	1	2	3	4
10	1 2 3 4	1 2 3 4					1	2	1	2	3	4	1	2	1	2	3	4
11	1 2 3 4	1 2 3 4					1	2	1	2	3	4	1	2	1	2	3	4
12	1 2 3 4	1 2 3 4					1	2	1	2	3	4	1	2	1	2	3	4

B. **Socio-economic Background**

B1. Do you or members of your household have any of these items?

		Yes	No
a)	color TV	1	2
b)	video player	1	2
c)	refrigerator	1	2
d)	telephone	1	2
e)	furniture set (store bought)	1	2
f)	air conditioner	1	2
g)	motorcycle	1	2
h)	car/truck	1	2

B2. What type of house is R living in?

1 hut or shack
2 one story wooden or bamboo house
3 wooden house, raised floor on posts, with open lower level
4 wooden house, with lower level walled in
5 one story cement/stucco house
6 two or more story cement/stucco house
7 wooden shop-house/row-house
8 cement row house/shop-house/townhouse
9 other (specify) _____

B2a. What material makes up the roof or the house?

1 thatch/leaves/grass
2 corrugated tin
3 shingles
4 corrugated cement
5 tiles
6 other (specify) _____

B2b. Does house have running water inside the house?

1 yes
2 no

B3. Who owns the house that you live in?

1 self (and/or spouse)
2 parents or parents-in-law
3 one of R's children
4 landlord (pays rent)
5 other (specify) _____

B4. Do you own any land?

1 yes (state number of rai _____)
2 no
3 other (specify) _____

B5. (*for interviewer to judge – do not ask respondent*)
Based on the appearance of the respondent's house, how do you judge the economic status of the household to be?

1 very well off
2 well off
3 average
4 below average but not very poor
5 very poor
9 did not see

B6. What has been your major occupation during your life? _____

B7. What all are your sources of support?
(C*ircle all that apply*)

1 own and/or spouse's work
2 own savings
3 rent/interest/investments
4 pension/lump sum
5 children
6 other relatives
7 donations/welfare

B7a. (if more than one source in B7) Of all of these, what is you most important source of support?

1 own and/or spouse's work
2 own savings
3 rent/interest/investments
4 pension/lump sum
5 children
6 other relatives
7 donations/welfare

B8. Clarify respondent's current marital status

1 currently married, living with spouse (*Skip to B12*)
2 currently married, not living with spouse (*Skip to B9*)
3 separated or divorced (*Skip to B9*)
4 widowed

B8a. How long ago did your spouse die?
_____ years _____ months

B8b. How old was your spouse when s/he died? _____ years old (*Skip to SB12*)

B9. How old is your (ex-)spouse? _____ years old

B10. Where is your (ex-)spouse living?
1 in same locality
2 elsewhere
9 do not know

B11. How long have you and your (ex-)spouse not been living together?
1 less than a year
(state months __)
2 1 year or more
(state years __)

B12. What has been your (former) spouse's major occupation during his/her life?
_____

B13. How many times have you been married? ___ times

B14. How many times has (was) your (most recent) spouse been married? ___ times

B15. Do you have any savings?
1 yes
2 no (*Skip to B16*)

B15a. Are your savings worth at least 10,000 Baht?
1 yes
2 no

B16. What is your economic status relative to others in your community?
1 much better
2 somewhat better
3 about average
4 below average but not much worse
5 much worse

B17. Do you or your household currently have any kind of health insurance or health benefits? (*Circle all that apply*)

1 none
2 government health card
3 welfare health card
4 elderly health card
5 civil service insurance
6 private insurance
7 other (specify) _____

B18. Do you or your household currently receive any kind of financial benefits from the government welfare or from NGOs?

1 yes (specify) _____
2 no

C. Children Matrix

C1. How many children do you have who are still living, including your own, step, and adopted children?

	Sons	Daughters
a) Own children		
b) Step children		
c) Adopted children		

Interviewer: Let me make sure I have this straight, in total you have ____ children including your own, step and adopted children, ___ who are sons and ___ who are daughters. Now I would like to ask you a few questions about each child.

C2. *Fill out the information below for all living children, starting with the oldest (include own, step and adopted children)*:

(a) child no.	(b) nick-name or 1st initial	(c) sex M F	(d) age	(e) birth year	(f) type of child 1=own 2=step 3= adopt	(g) resides where? 1=same house 2=next door/ nearby 3=same locality 4=same district 5=same province 6=elsewhere	(h) (if 3-24) attends school? yes no	(i) (if 6+) highest grade finished	(if 16 or older) (j) marital status 1=single 2=married 3=separated or divorced 4=widowed	(if 16 or older) (k) number of children
1		1 2			1 2 3	1 2 3 4 5 6	1 2		1 2 3 4	
2		1 2			1 2 3	1 2 3 4 5 6	1 2		1 2 3 4	
3		1 2			1 2 3	1 2 3 4 5 6	1 2		1 2 3 4	
4		1 2			1 2 3	1 2 3 4 5 6	1 2		1 2 3 4	
5		1 2			1 2 3	1 2 3 4 5 6	1 2		1 2 3 4	
6		1 2			1 2 3	1 2 3 4 5 6	1 2		1 2 3 4	
7		1 2			1 2 3	1 2 3 4 5 6	1 2		1 2 3 4	
8		1 2			1 2 3	1 2 3 4 5 6	1 2		1 2 3 4	

	Ask if 16 or older -- Questions refer to last 12 months and to couple if married																	
child no.	(l) did (name) work last year?		(m) type of work	(n) Has (name) given you money equal to a total of 1000+Baht?		(o) Has (name) given you food or other gifts equal to a total of 1000+ Baht?		(p) Have you given (name) money equal to a total of 1000+ Baht?		(q) Have you given (name) food or other gifts equal to a total of 1000+ Baht?		(r) (if child not in household) How often do you see (name)? 1 daily 2 at least weekly 3 at least monthly 4 several times a year 5 at least every year 6 less than every year					
	yes	no		yes	no	yes	no	yes	no	yes	no						
1	1	2		1	2	1	2	1	2	1	2	1	2	3	4	5	6
2	1	2		1	2	1	2	1	2	1	2	1	2	3	4	5	6
3	1	2		1	2	1	2	1	2	1	2	1	2	3	4	5	6
4	1	2		1	2	1	2	1	2	1	2	1	2	3	4	5	6
5	1	2		1	2	1	2	1	2	1	2	1	2	3	4	5	6
6	1	2		1	2	1	2	1	2	1	2	1	2	3	4	5	6
7	1	2		1	2	1	2	1	2	1	2	1	2	3	4	5	6
8	1	2		1	2	1	2	1	2	1	2	1	2	3	4	5	6

D. Measures of well being: three years ago versus today

D1. How happy would say you are these days?
1 very happy
2 somewhat happy
3 neither happy nor sad
4 not very happy
5 not at all happy

D1a. Compared to 3 years ago, would you say you are happier now or were you happier then?
1 much happier now
2 somewhat happier now
3 about the same (*Skip to D2*)
4 somewhat happier then
5 much happier then

D1b. What is the main reason why your happiness has changed? _____
_____

D2. At present how comfortable or difficult would you say your financial situation is?
1 very comfortable
2 comfortable
3 neither comfortable or difficult
4 somewhat difficult
5 very difficult

D2a. Compared to 3 years ago, would you say that your financial situation is better or worse?
1 much better
2 somewhat better
3 about the same (*Skip to D3*)
4 somewhat worse
5 much worse

D2b. What is the main reason why your financial situation has changed? _____
_____

D3. Currently are you (and/or your spouse) in debt?
1 yes
2 no (*Skip to D4*)

D3a. How serious a burden is this debt for you (and/or your spouse)?

1 very serious
2 somewhat serious
3 not very serious

D3b. Can you tell us approximately by how much you are in debt?

_____ Baht 9 do not know

(If can not state amount ask) Was it as much as ------- ?

(*Probe each amount starting at lowest and stop at highest level or at first 'no' answer*)

1000	1 yes 2 no
5000	1 yes 2 no
10000	1 yes 2 no

9 do not know

D3c. Can you tell us the main reason you are in debt? _____

_____

D4. Three years ago were you in debt?

1 yes
2 no (*Skip to D5*)

D4a. How serious a burden was this debt for you (and/or your spouse) three years ago?

1 very serious
2 somewhat serious
3 not very serious

D4b. Can you tell us approximately how big this debt was three years ago?

_____ Baht 9 do not know

(If can not state amount ask) Was it as much as ------- ?

(*Probe each amount starting at lowest and stop at highest level or at first 'no' answer*)

1000	1 yes 2 no
5000	1 yes 2 no
10000	1 yes 2 no

9 do not know

D4c. Can you tell us the main reason for your debt three years ago? _____

_____

D5. Compared to 3 years ago, would you say you (and your spouse) now receive more, less, or about the same financial support in total from your all your children together?

1 much more
2 somewhat more
3 about the same (*Skip to D6*)
4 somewhat less
5 much less
6 do not receive any now but did then
7 did not receive any then but do now
8 did not receive any then or now (*Skip to D6*)
9 currently has no living children (*Skip to D6*)

D5a. What is the main reason the amount you receive from your children has changed? _____

_____

D6. In general, do you feel you have good relations with most of your neighbors and other people in the community?

1 very good
2 somewhat good
3 neither good nor bad
4 not very good
5 not at all good

D6a. Compared to 3 years ago, would you say your relations with most of your neighbors and other people in the community are better or worse?

1 much better
2 somewhat better
3 about the same (*Skip to D7*)
4 somewhat worse
5 much worse

D6b. What is the main reason your relations with neighbors and other people in the community have changed?

_____

D7. In general, how would you say your physical health is at present?

1 excellent
2 pretty good
3 average
4 not so good
5 poor

D7a. Compared to most people your age, would you say your health is better or worse?

1 better
2 the same
3 worse

D7b. How would you say your physical health at present compares to 3 years ago?

1 much better
2 somewhat better
3 about the same
4 somewhat worse
5 much worse

D7x. *Interviewer: Based on B8 check if respondent is married and living with spouse*		yes (*Ask D8*)
		no, (*go to section E*)

D8. In general, how would you say your spouse's physical health is at present?

1 excellent
2 pretty good
3 average
4 not so good
5 poor

D8a. Compared to most people his/her age, would you say your spouse's health is better or worse?

1 better
2 the same
3 worse

D8b. How would you say your spouse's physical health at present compares to 3 years ago?

1 much better
2 somewhat better
3 about the same
4 somewhat worse
5 much worse

E. Death of Adult Child

E1. Have any of your children died within in the last 5 years?
1 yes
2 no (terminate interview and go to Section I at end of questionnaire)

E2. How many children have died within the last 5 years?
___ number

E3. Please tell me about the child(ren) who died.

	1st child	2nd child	3rd child
Nick name			
a) Year of death			
b) Month of death			
c) Sex: 1=son 2=daughter	1=son 2=daughter	1=son 2=daughter	1=son 2=daughter
d) Age at death			
e) Cause of death:	1 TB/lung infection 2 brain infection 3 suicide 4 accident 5 AIDS 6 other (specify)	1 TB/lung infection 2 brain infection 3 suicide 4 accident 5 AIDS 6 other (specify)	1 TB/lung infection 2 brain infection 3 suicide 4 accident 5 AIDS 6 other (specify) ....
f) highest grade completed			

(*Interviewer: If this is a case where there is no child who died of or is suspected of dying of the target disease terminate interview and go to section I at end of questionnaire. If this is a case with a death of a child due to target disease or suspected to be due to target disease (as determined by screening information on cover page), continue the interview even if the respondent does not state the cause of death is due to target disease. If there is more than one child who died, ask about the most recent death occurring within the window period.*)

E4. I would like to ask you about your child who died recently. In general, what type of person would you say (name) was before being ill? Was s/he a good person, average, or problematic? (*Circle all that are mentioned*)
1 good person/well liked person
2 normal/average person
3 frequent commercial sex patron (for man)
4 promiscuous (for woman)
5 bad/delinquent person
6 other (specify) _____

E4a. Would you say that (name) got along well with others in your community?
1 yes
2 no (specify) _____
3 never lived in this community

E5. What was (name's) main occupation before being ill? _____

E6. What was name's marital status at time of death?
1 single (never married) and has no children (*Skip to E16*)
2 married, living with spouse (*Skip to E9*)
3 married but not living with spouse
4 separated or divorced
5 widowed (*Skip to E12*)
6 never married but has children (*Skip to E14*)

E7. Did the fact that (name) was becoming ill contribute to the separation from his/her spouse?
1 yes
2 no
3 other (specify)_____

E8. Did (name's) spouse go to live with parents since (name) died (or since spouse left (name))?
1 yes
2 no
9 do not know.

E9. Did (name's) spouse remarry?
1 yes
2 no
9 do not know.

E10. Is name's spouse still alive?
1 yes
2 no (*Skip to E12*)
9 do not know (*Skip to E13*)

E11. Where is (name's) spouse living now?
1 with R (*Skip to E13*)
2 next door or very nearby to respondent (*Skip to E13*)
3 in same locality as respondent (*Skip to E13*)
4 elsewhere (specify) _____ (*Skip to E13*)
9 do not know (*Skip to E13*)

E12. What was the cause of death of name's spouse?

1 TB/lung infection
2 brain infection
3 suicide
4 accident
5 AIDS
6 other (specify) _____

E13. What is (was) (name's) spouse's main occupation? _____

E14. Did (name) have any children?

1 yes
2 no (*Skip to E16*)

E15. Could you please tell me about (name's) children? (*If more than 4 children, use an additional questionnaire to complete*)

	Child 1	Child 2	Child 3	Child 4
a. Sex:	1=son 2=daughter	1=son 2=daughter	1=son 2=daughter	1=son 2=daughter
b. Current age	____ yrs old (0=under1; 98=dead)	____ yrs old (0=under1; 98=dead)	____ yrs old (0=under1; 98=dead)	____ yrs old (0=under1; 98=dead)
c. Since (name's) death has the child lived with you?	1 yes all the time (*Skip to e*) 2 yes, part of time and still lives with me (*Skip to e*) 3 yes, part of time but not now 4 no	1 yes all the time (Skip *to e*) 2 yes, part of time and still lives with me (*Skip to e*) 3 yes, part of time but not now 4 no	1 yes all the time (*Skip to e*) 2 yes, part of time and still lives with me (*Skip to e*) 3 yes, part of time but not now 4 no	1 yes all the time (*Skip to e*) 2 yes, part of time and still lives with me (*Skip to e*) 3 yes, part of time but not now 4 no
d. With whom does child live now? (*Circle all that apply*)	1 surviving parent 2 (name's) spouse's parents 3 other (specify) ____ 8 child died 9 does not know	1 surviving parent 2 (name's) spouse's parents 3 other (specify) ____ 8 child died 9 does not know	1 surviving parent 2 (name's) spouse's parents 3 other (specify) ____ 8 child died 9 does not know	1 surviving parent 2 (name's) spouse's parents 3 other (specify) ___ 8 child died 9 does not know
e. (If child is alive and 3+ yrs old) Is the child attending school?	1 yes (in grade _____) 2 no (but completed grade _____) 3 no, never attended 9 does not know	1 yes (in grade _____) 2 no (but completed grade _____) 3 no, never attended 9 does not know	1 yes (in grade _____) 2 no (but completed grade _____) 3 no, never attended 9 does not know	1 yes (in grade ____) 2 no (but completed grade _____) 3 no, never attended 9 does not know

f. (If child is between 3 and 16 and not attending school) Why is the child not in school? (*Circle all that apply*)	1 can not afford 2 child does not want 3 child already finished desired level 4 child is too ill/weak 5 school does not allow 6 other (specify) ____ 7 too young 9 does not know	1 can not afford 2 child does not want 3 child already finished desired level 4 child is too ill/weak 5 school does not allow 6 other (specify) ____ 7 too young 9 does not know	1 can not afford 2 child does not want 3 child already finished desired level 4 child is too ill/weak 5 school does not allow 6 other (specify) ____ 7 too young 9 does not know	1 can not afford 2 child does not want 3 child already finished desired level 4 child is too ill/weak 5 school does not allow 6 other (specify) ___ 7 too young 9 does not know

E16. How long before dying did (name) first start to show signs of being ill?
(*Probe for start of any symptoms, not just severe symptoms*).

___ months
___ years
___ never showed signs of being ill *(Skip to E19)*
___ does not know

E17. Was (name) ill all the time between first being ill and dying or did s/he get better and worse off and on?

1 Continuously ill
2 got better and worse, off and on
3 was ill for just a short time
9 does not know (*Skip to E19*)

E18. How long was (name) seriously ill that s/he needed someone to give personal care before dying?

___ total number of months (if more than one year state in terms of months)
___ total weeks if less than a month

E19. Where was (name) living just before s/he died?

1 with respondent (*Skip to E22*)
2 next door or very nearby to respondent (*Skip to E22*)
3 in same locality as respondent) (*Skip to E22*)
4 elsewhere (specify) _____

E20. Did you ever go to spend time with (name) during the time s/he was ill?

1 yes
2 no (*Skip to E22*)

E21. How much time in total did you spend with (name) during the time s/he was ill?
_____ years _____ months _____ weeks _____ days

E22. At the time (name) died, did s/he die in the hospital or at home?
1 in hospital
2 on way to hospital
3 at home
4 elsewhere (specify) _____
9 Do not know

E23. How long had (name) been living where s/he had been living just before dying?
1 all the time (*Skip to E33*)
2 more than 5 years
3 less than 5 years (State: ____ years ____ months ____ weeks ____ days)
4 went back and forth

E24. Between the time of first showing signs of symptoms and when name died, did (name) live in the same place the entire time or did s/he change residence?
1 same place (*Skip to E33*)
2 changed residence

E25. How many times did (name) change residence after first showing signs of becoming ill?
____ number of times

Please tell me about the changes of residence

	a) Last move	b) Move before last
E26. From where did (name) move?	1 from R's home 2 next door or nearby 3 from R's locality 4 elsewhere (specify)	1 from R's home 2 next door or nearby 3 from R's locality 4 elsewhere (specify) .....
E27. With whom all was (name) living before the move? (*Circle all that apply including the respondent and the respondent's spouse (i.e. mother, father), if appropriate.*)	0 alone, lived by self 1 spouse 2 children under age 16 3 adult son (16+) 4 adult daughter (16+) 5 father 6 mother 7 father-in-law 8 mother-in-law 9 brother 10 sister 11 grand father 12 grand mother 13 friends/coworkers 14 other (specify) ____	0 alone, lived by self 1 spouse 2 children under age 16 3 adult son (16+) 4 adult daughter (16+) 5 father 6 mother 7 father-in-law 8 mother-in-law 9 brother 10 sister 11 grand father 12 grand mother 13 friends/coworkers 14 other (specify) ____

	99 R does not know	99 R does not know
E28. To where did (name) move?	1 to R's home 2 next door or nearby 3 to R's locality 4 elsewhere (specify)	1 to R's home 2 next door or nearby 3 to R's locality 4 elsewhere (specify) .....
E29. When (name) moved, who else moved with him/her? (*Circle all that apply*)	1 spouse 2 children (specify no. ___) 3 others (specify) _____ _____	1 spouse 2 children (specify no. ___) 3 others (specify) _____ _____
E30. How long did (name) live at the new residence?	_____ years _____ months _____ weeks (*Check with E23*)	_____ years _____ months _____ weeks
E31. Did (name) move because of illness?	1 no (specify reason_____ _____) 2 yes	1 no (specify reason_____ _____) 2 yes
E32. (If yes) which of the following were reasons why (name) moved. (*Circle all that apply).*	1 Needed someone to care for him/her 2 Spouse died 3 Spouse deserted 4 Lost job or could not work any more 5 Could not support self financially 6 For psychological support (afraid or lonely) 7 Came home to die 8 Other (specify) _____ _____ _____ 9 R does not know	1 Needed someone to care for him/her 2 Spouse died 3 Spouse deserted 4 Lost job or could not work any more 5 Could not support self financially 6 For psychological support (afraid or lonely) 7 Came home to die 8 Other (specify) _____ _____ _____ 9 R does not know

E33. Just before (name) died, who all was living in the household with (name)?
(*Circle all that apply including the respondent and the respondent's spouse (i.e. mother, father), if appropriate.*)

0 alone, lived by self
1 spouse
2 children under age 16
3 adult son (16+)
4 adult daughter (16+)
5 father
6 mother
7 father-in-law
8 mother-in-law
9 brother
10 sister
11 grand father
12 grand mother
13 friends/coworkers
14 other (specify) _____
99 R does not know

F. Economic Effects Associated with Child Death

Often when people are very sick, they will have expenses for things such as medicine, food, clothing, transportation, etc., that must be paid by someone else. They also need to be cared for or assisted in various ways when they are sick. I would like to know who helped in these ways.

F1. At the time (name) was ill, did any kind of health insurance pay for any of his/her medical costs?

(*Circle all that apply*)

1 no (*Skip to F2*)
2 government health card
3 welfare health card
4 civil service insurance
5 government social security system
6 yes, other private insurance
7 other (specify) _____
9 do not know (*Skip to F2*)

F1a. Was having the health insurance much of a help in covering the medical expenses?

1 helped very much
2 helped only some
3 helped very little or not at all
9 do not know

F2. Did (name) or his/her family members receive any welfare payments or financial assistance from the government or NGOs in connection with his/her illness.

1 yes (specify program) _____
2 no (*Skip to F3*)
9 do not know

F2a. Is this assistance still being provided to anyone in (name's) family?

1 yes (specify to whom) _____
2 no
3 other (specify) _____
9 do not know

F2b. About how long was this financial assistance provided?

(express in months)

_____ months
99 do not know

F2c. About how much did (name) or (name)'s family receive in total from this assistance?

_____ Baht 9 do not know

(If can not state amount ask) Was it as much as ------- ?

(*Probe each amount starting at lowest and stop at highest level or at first 'no' answer*)

1000	1 yes 2 no
5000	1 yes 2 no
10000	1 yes 2 no

9 do not know

F2d. About how much would you say this assistance helped defray the expenses to (name) and his/her family for the expenses associated with (name's) illness?

1 a great deal
2 some
3 very little
9 do not know

F3. Can you tell (besides insurance and welfare) who all helped pay the living and medical expenses of (name) when s/he was sick? (*Circle all that apply: Note the respondent and spouse are designated as mother and father*)	F3a. Who was the primary source of payment for these expenses? (*try to identify one or at most two persons who paid the greatest share of expenses*)
1 (Name) him/herself. 2 (Name's) spouse 3 (Name's) son(s) 4 (Name's) daughter(s) 5 (Name's) mother 6 (Name's) father 7 (Name's) brother(s) 8 (Name's) sister(s) 9 (Name's) father in law 10 (Name's) mother in law 11 (Name's) grandmother 12 (Name's) grandfather 13 Other male relatives (specify) _____ 14 Other female relatives (specify) _____ 15 Male friends 16 Female friends 17 Other (specify): _____	1 (Name) him/herself. 2 (Name's) spouse 3 (Name's) son(s) 4 (Name's) daughter(s) 5 (Name's) mother 6 (Name's) father 7 (Name's) brother(s) 8 (Name's) sister(s) 9 (Name's) father in law 10 (Name's) mother in law 11 (Name's) grandmother 12 (Name's) grandfather 13 Other male relatives (specify) _____ 14 Other female relatives (specify) _____ 15 Male friends 16 Female friends 17 Other (specify): _____

F3x.	*Interviewer: Check if either the respondent or respondent's spouse helped pay for any of the expenses*		Did not (*Skip to F4x*)
			Did help (*Ask F4*)

F4. What kinds of things did you help pay for related to (name's) illness? (*Ask about each*)

Type of expense	Did R and/or spouse pay for expense	
	yes	no
a) Medicine	1	2
b) Doctor/clinic/hospital fees	1	2
c) Transportation	1	2
d) Food	1	2
e) Other (specify):	1	2
f) Other (specify):	1	2

F4a. Overall how much did you (and your spouse) spend all together on (name) as a result of his/her illness?

_____ Baht 9 do not know

(If can not state amount ask) Was it as much as ------- ?

(*Probe each amount starting at lowest and stop at highest level or at first 'no' answer*)

1000	1 yes 2 no
5000	1 yes 2 no
10000	1 yes 2 no

9 do not know

F4x.	*Interviewer: Examine E6 and E14 and indicate if the child who died was ever married and/or had children at the time of illness*		Single and no children (code 1 in E6) (*Skip to F6*)
			Ever married or had children (codes 2-6 in E6) (*Ask F5*)

F5. Did you or your spouse have to pay for any expenses for (name's) (spouse and/or children) when (name) was ill or after (name) died?

1 yes

2 no (*Skip to F6*)

F5a What expenses did you pay for? (*probe for each and indicate all that apply*)

Type of expense	Did you and/or spouse pay for expense		Do you expect to pay in future?	
	yes	no	yes	no
a) Medicine	1	2	1	2
b) Transportation	1	2	1	2
c) Food	1	2	1	2
d) Clothing	1	2	1	2
e) School expenses	1	2	1	2
f) Other (specify):	1	2	1	2
g) Other (specify):	1	2	1	2

F6. How much was the total cost of the funeral? (amount _____ Baht)
(If can not state amount ask) Was it as much as ------- ? 9 do not know
(*Probe each amount starting at lowest and stop at highest level or at first 'no' answer*)

5000	1 yes 2 no
10000	1 yes 2 no
20000	1 yes 2 no
50000	1 yes 2 no

9 do not know

F6a. Excluding money you got back from funeral societies and from contributions, how much did you (and your spouse) have to pay for the funeral.
State approximate amount _____ Baht) (*write 0 if nothing*) 9 do not know
(If can not state amount ask) Was it as much as ------- ?
(*Probe each amount starting at lowest and stop at highest level or at first 'no' answer*)

5000	1 yes 2 no
10000	1 yes 2 no
20000	1 yes 2 no
50000	1 yes 2 no

9 do not know

F6x. *Interviewer: Based on previous answers, check if R or R's spouse helped pay for any of the dead child's expenses while ill, the funeral expenses or the dependents expenses*		No (*Skip to F9*)
		Yes (*Ask F7*)

F7. Thinking about all the expenses you had in connection with your child's illness and/or funeral, would you say that these expenses created financial difficulty for you?

1 quite a lot
2 some but not much
3 no
4 other(specify) _____

F7a. As a result of the expenses you had in connection with your child's illness and/or funeral, did you (or your spouse) have to borrow any money to cover these expenses?

1 yes (State amount _____ Baht) 9 do not know
(*If can not state amount ask*) Was it as much as ------- ?
(*Probe each amount starting at lowest and stop at highest level or at first 'no' answer*)

5000	1 yes 2 no
10000	1 yes 2 no
20000	1 yes 2 no
50000	1 yes 2 no

9 do not know

2 no (Skip to F7c)

F7b. Have you paid off this debt yet?

1 yes, in entirety
2 most of it
3 only some of it
4 none of it
5 other(specify) _____

F7c. As a result of the expenses you had in connection with your child's illness and/or funeral, did you (or your spouse) have to sell any of your land or belongings to raise money.

1 yes
2 no (*Skip to F8*)

F7d. What did you sell? (*Circle all that apply*)

1 all or most of my/our land (state amount received _____ Baht)
2 some of my/our land (state amount received _____ Baht)
3 car/truck/motorcycle (state amount received _____ Baht)
4 gold or jewelry
5 other (specify) _____; amount received _____ Baht

F8. Did you or your spouse have to take on additional work beyond what you normally were doing in order to help pay for your child's illness and/or funeral?

1 yes
2 no (*Skip to F9*)

F8a. Please tell me who had to take on additional work.

1 the respondent only
2 the respondent's spouse only
3 both the respondent and respondent's spouse

F8b. Is this extra work still being taken on?

1 yes
2 no

F8c. What sorts of activities did you engage in to earn extra income?

Type of income activity	Hours per week	Income per week	Duration of activity (e.g., 5 months)
a) Hired labor			..... weeks ..... months ..... yrs
b) Selling goods			..... weeks ..... months ..... yrs
c) Piecework at home			..... weeks ..... months ..... yrs
d) Other:			..... weeks ..... months ..... yrs
e) Other:			..... weeks ..... months ..... yrs

F9. During the year before becoming seriously ill, had (name) been contributing income to the household?

1 yes
State amount: (_____ Baht per month) *Skip to F9b*
or (_____ Baht per year) *Skip to F9b*
2 yes but can not state amount
3 no (*Skip to F10*)

F9a. Can you say if the amount contributed during the year was less than 1000, 1000-5000 or more that 5000 Baht?

1 less than 1000
2 1000-5000
3 more than 5000
9 can not say/do not know

F9b. Before becoming ill, was (name) the main provider for your household?

1 yes (*Skip to F10*)
2 no
3 other (specify) _____

F9c. How much of the support of the household did (name) contribute during the year before s/he became ill?

1 more than half
2 about half
3 some but less than half
4 only a little
5 other (specify) _____

F10. Please remind me, was (name) living with you during the year before s/he became ill?

1 yes, the whole year
2 went back and forth
3 part of the year
4 no (*Skip to F12x*)

F11. During the year before becoming seriously ill, had (name) been helping with household chores or household economic activities of your household?

1 yes, regularly
2 only irregularly
3 no

F12. Since (name) became ill and died, has any one else moved in to help contribute to the support and maintenance of the household?

1 yes
2 no (*Skip to 12x*)

F12a. Who moved in?

	Relationship to R: 1=another child 2=grand child 3=sibling 4= Other (specify)	Sex		Age	Still present?		Duration of residence since moving into household
		m	f		yes	no	
1	1 2 3 4	1	2		1	2	..... years ..... months
2	1 2 3 4	1	2		1	2	..... years ..... months
3	1 2 3 4	1	2		1	2	..... years ..... months
4	1 2 3 4	1	2		1	2	..... years ..... months

F12x. *Interviewer: Check from F9 and F11 if deceased child contributed income or labor to R's household.*		No (*Skip to section G*)
		Yes (*Ask F13*)

F13. Has the fact that (name) is no longer contributing to the income and/or labor of your household made your financial situation more difficult?

1 much more difficult
2 somewhat more difficult
3 no
4 Other (specify): _____

G. Care taking

G1. People who are seriously ill usually need to be given care and assistance. This includes both daily personal care such as help with eating, dressing, bathing, moving around in the house as well as assistance with their affairs outside the house such as transportation to see doctors, going to buy medicine, or managing the ill person's financial and other personal affairs. We would like to ask both about who helps provide personal care in the household and who provides assistance for matters outside the household in which the ill person is staying.

G1a. Who all helped give personal care within the household to (name) when s/he was sick? (*Circle all that apply: Note the respondent and spouse are designated as mother and father*)	G1b. Who was the **primary** person who cared for (name) when he was ill? (*try to identify one or at most two persons gave the greatest share of care*)	G1c. Who all helped assist (name) in his/her needs outside the household when s/he was sick? (*Circle all that apply*)	G1d. Who was the **primary** person who assisted (name) in his/her needs outside the household? (*try to identify one or at most two persons gave the greatest share of care*)
1 (Name) cared for self.	1 (Name) cared for self.	1 (Name) cared for self.	1 (Name) cared for self.
2 (Name's) spouse	2 (Name's) spouse	2 (Name's) spouse	2 (Name's) spouse
3 (Name's) son(s)	3 (Name's) son(s)	3 (Name's) son(s)	3 (Name's) son(s)
4 (Name's) daughter(s)	4 (Name's) daughter(s)	4 (Name's) daughter(s)	4 (Name's) daughter(s)
5 (Name's) mother	5 (Name's) mother	5 (Name's) mother	5 (Name's) mother
6 (Name's) father	6 (Name's) father	6 (Name's) father	6 (Name's) father
7 (Name's) brother(s)	7 (Name's) brother(s)	7 (Name's) brother(s)	7 (Name's) brother(s)
8 (Name's) sister(s)	8 (Name's) sister(s)	8 (Name's) sister(s)	8 (Name's) sister(s)
9 (Name's) father in law	9 (Name's) father in law	9 (Name's) father in law	9 (Name's) father in law
10 (Name's) mother in law	10 (Name's) mother in law	10 (Name's) mother in law	10 (Name's) mother in law
11 (Name's) grandmother	11 (Name's) grandmother	11 (Name's) grandmother	11 (Name's) grandmother
12 (Name's) grandfather	12 (Name's) grandfather	12 (Name's) grandfather	12 (Name's) grandfather
13 Other male relatives (Specify)_____	13 Other male relatives (Specify)_____	13 Other male relatives (Specify)_____	13 Other male relatives (Specify)_____
14 Other female relatives (Specify)_____	14 Other female relatives (Specify)_____	14 Other female relatives (Specify)_____	14 Other female relatives (Specify)_____
15 Male friends	15 Male friends	15 Male friends	15 Male friends
16 Female friends	16 Female friends	16 Female friends	16 Female friends
17 Other (*specify*): _____ _____	17 Other (*specify*): _____ _____	17 Other (*specify*): _____ _____	17 Other (*specify*): _____ _____

G1x. *Interviewer: Examine the table above and indicate if either the respondent or respondent's spouse provided any care or assistance*		Both (*Ask G2*)
		Only one including non-married R (*Skip to G3*)
		Neither (*Skip to G8x*)

G2. Between you and your spouse, who provided more of the personal care in the household?

1 the respondent
2 the spouse
3 both equally
9 can not say

G2b. Between you and your spouse, who provided more of the assistance outside the household (e.g. transportation, going to buy things, managing affairs)?

1 the respondent
2 the spouse
3 both equally
9 can not say

G3. What kinds of things did you (and/or your spouse) do to help (name) when s/he was ill? (*probe each and circle all that apply*)

Type of activity	Provides any of this type of help?	
	yes	no
a) Preparing food	1	2
b) Bathing	1	2
c) Cleaning: laundry, dishes	1	2
d) Dressing	1	2
e) Feeding	1	2
f) Watching over	1	2
g) Lifting and moving, e.g., from bed to chair	1	2
h) Helping with the toilet, changing soiled linens	1	2
i) Preparing and giving medicine (pills or oral fluids)	1	2
j) Cleaning wounds	1	2
k) Shopping for food	1	2
l) Transportation, e.g., taking to clinic or hospital	1	2
m) Consulting with health care providers	1	2
n) Helping apply for welfare benefits for (name)	1	2
o) Arranging legal and financial affairs of (name)	1	2
p) Other (specify):	1	2
q) Other (specify):	1	2

G4. How long were you (and/or your spouse) giving care to (name) in total?
_____ years _____ months _____ weeks _____ days

G5. Overall, during the caregiving period, how much of your (and/or your spouse's) time were spent doing these things?

Respondent	R's spouse (if applicable)
1 a great deal of time	1 a great deal of time.
2 some of time.	2 some of time.
3 only a little time	3 only a little time
4 other (specify).....	4 other (specify).....

G5a. Overall, how difficult would you say it has been for you (and/or your spouse) to provide this care to (name)?

Respondent	R's spouse (if applicable)
1 extremely difficult	1 extremely difficult
2 somewhat difficult	2 somewhat difficult
3 a little difficult	3 a little difficult
4 not difficult	4 not difficult
5 other (specify).....	5 other (specify).....

G6. During the time that you (and/or you spouse) were caring for (name), did you and/or your spouse experience any of the following health problems that related to care giving? (*Probe for each and check all that apply.)*

Health problem	These columns refer to the Respondent (if respondent provided care)				These columns refer to the respondent's spouse (if spouse provided care)			
	Did you experience the symptom?		(If yes) How often?		Did your spouse experience the symptom?		(If yes) How often?	
	yes	no	often	not often	yes	no	often	not often
a) Strained muscles	1	2	1	2	1	2	1	2
b) Headaches/ Stomach aches	1	2	1	2	1	2	1	2
c) Tiredness or fatigue	1	2	1	2	1	2	1	2
d) Insomnia	1	2	1	2	1	2	1	2
e) Nervousness or anxiousness	1	2	1	2	1	2	1	2
f) Other: (specify)	1	2	1	2	1	2	1	2

G7. What was the **most** difficult aspect of caring for (name)? Explain. _____

G8. Did you (and/or your spouse) have to stop or reduce working because of caregiving responsibilities during the time your child was ill?

1 respondent stopped or reduced work
2 respondent's spouse stopped or reduced work
3 Both respondent and spouse stopped or reduced work
4 neither respondent nor spouse stopped or reduced work (*Skip to G8x*).

	These columns refer to the Respondent (if applicable)	These columns refer to the Respondent's spouse (if applicable)
G8a. What type of work was stopped or reduced?		
G8b. For how long a period was the work stopped or reduced	..... weeks ..... months	..... weeks ..... months
G8c. During the period you reduced or stopped working about how much income was lost as a result?	_____ Baht (If can not state amount ask) Was it as much as ------- ? 1000 Baht 1 yes 2 no 5000 Baht 1 yes 2 no 10000 Baht 1 yes 2 no	_____ Baht (If can not state amount ask) Was it as much as ------- ? 1000 Baht 1 yes 2 no 5000 Baht 1 yes 2 no 10000 Baht 1 yes 2 no

G8d. Did the fact that you (and/or your spouse) had to stop or reduce working because of caregiving responsibilities create financial hardship for your household?

1 a lot
2 some hardship
3 a little
4 no
5 other (specify) _____

G8x Interviewer: Check E15 and indicate if (name) had any children.		yes, had children (*ask G9*)
		no, did not have children (Skip to *G12*)

G9. Did you (and/or your spouse) have to help take care of (name's) children during the time (name) was ill or after (name) died?

1 yes
2 no (*Skip to G12*)

G10. Did you (and/or your spouse) have to do any of the following things for (name's) dependents while (name) was ill of after (name) died? (*probe each and check all that apply*)

Type of activity	Do you provide this type of Help?		Will you continue this help in future?	
	yes	no	yes	no
a) Watching the children	1	2	1	2
b) Taking children to school	1	2	1	2
c) Preparing food	1	2	1	2
d) Bathing	1	2	1	2
e) Cleaning, laundry, dishes,	1	2	1	2
f) Dressing	1	2	1	2
g) Other (specify):	1	2	1	2
h) Other (specify):	1	2	1	2

G11. How long were you (and/or your spouse) giving caring for (name's) dependents in total (up to now)?

_____ years _____ months _____ weeks _____ days

G12. During the time (name) was ill were you taking care of anyone else who needed care or assistance?

1 yes
2 no (*Skip to G13*).

G12a. Whom else were you caring for?

1 Spouse
2 Sibling
3 Other child
4 Friend
5 Parent(s)
6 Other (specify): _____

G13. Did you ever fear that you could become infected with the same illness that (name) had?

1 Often
2 Sometimes
3 Never/no.
4 Other (specify) _____

H. **Community reaction** (*If non-family members are present and can over hear interview, ask them to leave; if it is not possible to get sufficient privacy at this point in the interview skip Section H and go to Section I*)

H1. Did neighbors know about your child's illness?

1 yes, all or most did
2 Only some did
3 No (*Skip to H8*)
9 do not know

H2. Did your neighbors know during the time of illness or after death?

1 During illness
2 Only after death (*Skip to H8*)
3 Some during illness, some after death
9 do not know

H3. During your child's illness, did any neighbors show sympathy or offer help for you and your ill child?

1 yes (*ask "What types of help or sympathy?" and go to table*).
2 no (*ask "Did any of your neighbors do any of the following things?" and go to table*).

Type of help or sympathy *(Read after the respondent is finished giving unprompted responses).*	Yes, unprompted	Yes, prompted	"No" to prompt	Don't know
a) Visited	1	2	3	9
b) Looked after your sick child	1	2	3	9
c) Brought some food	1	2	3	9
d) Brought some medicine	1	2	3	9
e) Gave advice (e.g., about food, care and medicine)	1	2	3	9
f) Provide transportation or went with you to the hospital	1	2	3	9
g) Other (Specify)	1	2	3	9
h) Other (Specify)	1	2	3	9

H4. Did some neighbors have negative reactions to you and your ill child during the time of the illness?

1 yes -- (*ask "What types of negative reactions?" and go to the table*).

2 no -- (*ask "Did any of your neighbors do any of the following things?" and go to the table*).

Type of negative reaction *(Read after the respondent is finished giving unprompted responses).*	Yes, unprompted	Yes, prompted	"No" to prompt	Don't know
a) Avoided talking to you or others in household	1	2	3	9
b) Gossip	1	2	3	9
c) Would not visit your home	1	2	3	9
d) Other (Specify).....	1	2	3	9
e) Other (Specify)	1	2	3	9

H4x. *Interviewer: Examine H3 and H4 and check if there were any positive or negative reactions.*		Both positive and negative (*Ask H5*)
		Only negative (*Skip to H6*)
		Only positive (*Skip to H8*)
		Neither positive nor negative (*Skip to H8*)

H5. All in all, would you say that during the illness of your child, your neighbors were more sympathetic or more negative to you and your ill child?

1 More sympathetic.

2 More negative.

3 Neutral

9 do not know

H6. How long did the negative reactions during the illness of your child last?

1 Less than a month and then ended

2 More than a month and then ended

3 Still ongoing

H7. Did you ever think about moving away because of the negative reaction?

1 yes

2 no

H8. Where was the funeral for your child held?

1 at home

2 in the local temple

3 not local temple but within 25 kilometers of R's locality

4 further than 25 km away from R's locality

H9. How many people attended your child's funeral?

1 many
2 a normal amount
3 not so many
4 had no funeral ceremony
5 Other (Specify): _____

H10. After the death of your child, did any neighbors show sympathy or offer help to you?

1 yes (*ask "What types of help or sympathy?" and go to the table*).
2 no (*ask "Did any of your neighbors do any of the following things?" and go to the table*).

Type of help or sympathy *(Read after the respondent is finished giving unprompted responses).*	Yes, unprompted	Yes, prompted	"No" to prompt	Don't know
a) Visited you and your family	1	2	3	9
b) Helped with the funeral arrangements or activities	1	2	3	9
c) Attended the funeral activities	1	2	3	9
d) Other (Specify)	1	2	3	9
e) Other (Specify)	1	2	3	9

H11. Did your neighbors show any negative reaction after the death of your child?

1 yes – (*ask "What types of negative reaction?" and go to table*).
2 no - (*ask "Did any of your neighbors do any of the following things?" and go to table*).

Type of negative reaction *(Read after the respondent is finished giving unprompted responses).*	Yes, unprompt-ed	Yes, prompted	"No" to prompt	Unsure/ DK	Does not apply
a) Avoided talking to you or others in your household	1	2	3	9	X
b) Gossip	1	2	3	9	X
c) Would not visit your home	1	2	3	9	X
d) Refused to attend the funeral (if local funeral)	1	2	3	9	8
e) Refused to eat or drink at the funeral (if local funeral)	1	2	3	9	8
f) Other (Specify)	1	2	3	9	X
g) Other (Specify)	1	2	3	9	X

H11x. *Interviewer: Examine H10 and H11 and check if there were any positive or negative reactions.*		
		Both positive and negative (*Ask H12*)
		Only negative (*Skip to H13*)
		Only positive (*Skip to H14*)
		Neither positive nor negative (*Skip to H14*)

H12. All in all, would you say that after the death of your child, your neighbors were more sympathetic or more negative to you and your child?

1 More sympathetic.
2 More negative.
3 Neutral
9 do not know

H13. How long after the death of your child, did the negative reactions last?

1 Less than a month and then ended
2 More than a month and then ended
3 Still ongoing

H14. Have any of the following shown sympathy or been helpful towards you and your child during the illness or after the death of your child?

	yes	no	other (specify)
a) Heath center staff	1	2	3 .....
b) Community health volunteer	1	2	3 .....
c) Village headman	1	2	3 .....

H15. Did any of them show negative reactions towards you and your child during the illness or after the death of your child?

	yes	no	other (specify)
a) Heath center staff	1	2	3 .....
b) Community health volunteer	1	2	3 .....
c) Village headman	1	2	3 .....

I. Closing and Interviewer's assessment of the Interview

Thank respondent for being will to be interviewed and ask if they have any questions they would like to ask. If appropriate spend some time chatting with the interviewees to help reduce any stress they may have experienced as a result of the interview. Be sure to fill out the following information. Do not ask these questions to the respondent.

I1. In case of a couple, who answered the questions?

1 the designated respondent answered all or almost all by his/her self
2 the designated respondent answered more than the spouse
3 both the designated respondent answered and spouse contributed substantially to interview
4 the spouse answered more that the designated respondent
5 the spouse answered all or almost all by his/her self

I2. How cooperative do you feel the respondent(s) was (were) in providing truthful and complete answers?

1 Very cooperative
2 Mostly cooperative
3 Not very cooperative

I3. How stressful do you feel the interview was for the respondent(s)?

1 very stressful
2 somewhat stressful
3 not stressful

I4. List anyone besides respondent (and spouse) who was present during interview (present means could hear)

a) Specify relation to R (e.g. child, neighbor, etc)	b) For how much of interview was person present?			c) Did the person participate in the interview?			
	all /most	some, but not most	only a little	quite a lot	some	a little	only listened
	1	2	3	1	2	3	4
	1	2	3	1	2	3	4
	1	2	3	1	2	3	4

I5. What is religion of respondent?

1 Buddhist
2 Islam
3 Christian
4 other (specify) _____

Time interview ends: _____ hour _____ minute

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