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**Data Collection Strategies for Studying the Impacts of  
AIDS on Older Parents: Lessons from Research in Thailand**

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**Data Collection Strategies for Studying the Impacts of AIDS on Older Parents:  
Lessons from Research in Thailand**

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## **Abstract**

The present report addresses the methodological challenges to collection of data on the situation of parents of adults who become ill and die of HIV/AIDS, describes and evaluates the different strategies adopted in our research on the topic in Thailand, and draws lessons for researchers who might wish to conduct related studies in other settings. The specific challenges we discuss involve the sensitivity of the topic, the extended time frame in which impacts may occur, case definition, obtaining an appropriate sample, the need to develop sensitive instruments, and the protection of confidentiality. We then describe in some detail five data collection strategies we developed during the course of our research in Thailand: interviews with key informants about individual AIDS cases and their families; open-ended interviews with AIDS parents; direct survey interviews with AIDS affected and non-AIDS affected parents; assisted self-administered questionnaires to persons living with HIV/AIDS; and extraction of information from welfare applications related to AIDS. To highlight the relative strengths and weaknesses of these different approaches, we compare them in terms of sample characteristics, selected results, and problems they posed for maintaining confidentiality. We conclude with the major lessons from our experience that we believe can help guide future research on this topic generally.

## I. Introduction

As the global AIDS epidemic expands, its wide-ranging impacts on those who are not infected become clearer. The economic, social, emotional, and physical well being of increasing numbers of surviving family members are being affected by the illness and death of those who succumb to the disease. AIDS orphans, young children of those who die, are the most vulnerable of family members left behind. Thus considerable attention and research has been directed towards them, although much still remains to be learned about their situation (USAID, UNAIDS, and UNICEF 2002). Since most adults who die of AIDS are in their 20s, 30s, and 40s, many also leave behind older-age parents who are typically in their 50s, 60s, and 70s. Not only does the number of these AIDS parents likely exceed that of AIDS orphans but, in their own way, they are also particularly vulnerable to an array of adverse consequences (Knodel and VanLandingham 2002; Knodel, Watkins, and VanLandingham 2003). Yet empirical research on the impact of the epidemic on AIDS parents is largely lacking. As a result, neither the plight of older-age parents of adults with AIDS nor their potential role in dealing with the epidemic are being addressed by programs designed to combat the epidemic or ameliorate its consequences.

There is clearly a need for methodologically sound empirical research to serve as the basis for formulating policy and programs that incorporate both the needs of parents of those who die in the AIDS epidemic and their potential to assist in addressing it. So far, despite the need, there is a lack of literature on methodology of HIV/AIDS impact studies generally and virtually no discussion specific to how research on the impact of parents might be conducted (Booyesen and Arntz 2003). To date, the most comprehensive study of the impact of the epidemic on older persons, and particularly on the parents of those who die, is one we have been conducting in Thailand since 1998 using a variety of quantitative and qualitative data collection strategies. Limited quantitative research on the topic has also been done in Tanzania and a mixed-method pilot study, sponsored by the World Health Organization, has recently been completed in Zimbabwe (Ainsworth and Dayton 2001; Dayton and Ainsworth 2002; World Health Organization 2002). In addition, several qualitative studies have been carried out by others in Ethiopia, Thailand and Uganda (Gurmessa 1999; Paul 2001; Williams and Tumwekwase 2001). The present report addresses the methodological challenges to collection of data on the situation of AIDS parents and describes and evaluates the different strategies adopted in our Thai project.

We focus on issues and strategies relevant to research on the direct consequences that older-age parents experience by virtue of having an adult child become ill and die of HIV/AIDS. In previous papers we have spelled out multiple potential pathways through which these direct micro-level consequences come about (see e.g. VanLandingham et al. 2000; Knodel, Watkins and VanLandingham, 2003). Older parents can also be indirectly influenced by the impact of the epidemic on the community, society and economy at large, as can other population subgroups (for reviews see e.g. Barnett 2002; Barnett, Whiteside, and Desmond 2001). Methodological issues related to the assessment of indirect impacts operating at the macro-level, important as they are, are beyond the scope of our present discussion.

Some of the issues faced by research on AIDS parents are common to studies of the impact of the epidemic on households, a topic that has received more attention but about which there is also only minimal methodological guidance (Aggleton and Warwick 1999; Barnett and Whiteside 2000; Kongsin, Jiamton, Watts, and Boonthum 2001). In at least one important respect, however, studies that focus on the impact on particular types of family members such as parents, children, or spouses are more straightforward. Households may dissolve or split as a result of the illness and death of a member, thus creating ambiguities as to just what the unit of study should be, and presenting difficulties for tracking a household over time (Booyesen and Arntz 2003; Urassa et al. 2001). In contrast, identification of particular family members remains unambiguous over time, although locating them can pose difficulties for data collection.

While each setting is unique, we believe at least some of the challenges we faced in designing and implementing data collection in Thailand are likely to resemble those that will confront researchers elsewhere who plan to study the impact of AIDS on the parents of those who die. Even in situations where the social and epidemiological circumstances may be rather different, understanding the strengths and weaknesses of the strategies we followed and considering the extent to which they are suitable for another particular setting can serve to stimulate thinking about appropriate solutions.

The remainder of this report is divided into four major sections. We first discuss the methodological challenges and constraints that confront research on AIDS parents in general. We then describe in some detail the data collection strategies we developed during the course of our research on the topic in Thailand. This is followed by a comparison of our various approaches with comments on their relative strengths and weaknesses. We conclude with the major lessons from our experience that we believe can help guide future research on this topic generally.

## **II. Methodological challenges and constraints facing research on AIDS parents**

Any study of the impact of AIDS on parents faces a number of challenges. These include the sensitivity of the topic, the extended time frame in which impacts may occur, case definition, obtaining an appropriate sample, developing sensitive instruments, and protecting confidentiality.

### *Sensitivity of the subject matter*

Perhaps the most obvious source of difficulty is the social and emotional sensitivity of the subject matter. The loss of an adult child, whether due to AIDS or due to any other reason, is typically a traumatic and emotionally difficult experience for a parent. Numerous studies have found that the death of an adult child is among the most distressful life experiences (DeVries, Lana, and Falck 1994; Moss, Leshner, and Moss 1986; Sanders 1980). Talking about it could thus be difficult for parents who may not wish to be reminded of their loss. Some parents, however, may welcome the opportunity to share their grief with someone willing to listen, even if it evokes strong emotional reactions.

Parents and other family members of someone who died of AIDS may perceive that the disease is stigmatized and feel shame or fear negative reaction if others in the community know the cause of death. This in turn may prevent them from being open to others, including outside researchers, about the loss of a child to AIDS. Some may even deny to themselves the true cause of death. The extent of stigma, both perceived and real, are likely to vary considerably over time and across settings but it is unlikely that it will be completely absent anywhere.<sup>1</sup>

### *Time frame*

Taking appropriate account of the time frame within which particular consequences can be expected to emerge must also be an explicit consideration in any research on the impacts on parents of adults with AIDS. As the conceptual frameworks for studying these impacts referred to above make clear, different pathways of impact operate within different time frames. Some impacts may be immediate and short term, occurring during the period of illness when the parent might be involved in caregiving or shortly after death when the funeral takes place and mourning is likely to be particularly intense. Others may be

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<sup>1</sup> For a discussion of stigma based on our research in Thailand see VanLandingham, Im-em, and Saengtienchai 2002.

prolonged or substantially delayed until a much later period when the parents' need for old-age support from adult children is more manifest.

The fact that living and caregiving arrangements of persons with HIV/AIDS often change during the course of their illness, as our research and that of others makes clear, bears directly on this issue. In particular, many HIV infected adult children who live elsewhere at the onset of symptoms return to stay with their parents only at later stages of illness, when they can no longer support or care for themselves (Brabant 1994; Ellis and Muschkin 1996; Knodel and VanLandingham 2003). In other cases, parents may be the ones who move, temporarily joining their ill child at the later stages of illness to provide care. As a result, the full extent of parental involvement in caregiving will not be evident until the adult child dies of AIDS. Other impacts may not be felt until long after the death of the deceased child, for example when the parents reach ages at which they are frail or no longer economically active and need to depend on adult children for care and support.

### *Case definition*

Choices need to be made regarding what constitutes a case for study. One important choice is whether the universe of cases for which data are being collected is defined as persons who die of AIDS (regardless of whether or not the parents are still surviving) or as the parents of such cases. This affects the base population to which the resulting estimates will refer. For example, only the former would allow an estimate of what proportion of adults who die of AIDS are cared for by a parent. In contrast, estimates of the proportion of AIDS parents who care for their ill adult child only require information on parents themselves. Perhaps even more importantly, as our experience in Thailand clearly illustrates and as discussed in some detail below, differences in the way these two types of cases are identified in practice can have implications for the selection biases that characterize the sample.

### *Obtaining an appropriate sample*

Probably the greatest challenge for research related to AIDS parents relates to obtaining a reasonably representative sample of such parents and/or their infected adult children. No country keeps a register of parents who lose an adult child to AIDS and few countries, especially in the developing world, maintain accurate, relatively complete, and accessible registers of persons who have been infected by HIV, are currently ill with AIDS, or who died of AIDS. Moreover, such registers may be purposely anonymous to protect confidentiality. Thus drawing a probability sample from them is rarely a feasible option. In some settings, registers of AIDS deaths may be available from local health facilities including hospitals and can serve as a sampling frame. However, if these are not uniformly available throughout a country and/or are incomplete where they are available, selectivity of cases has the potential to seriously skew results.

In the absence of registers for drawing a representative sample, one practical solution is to sample study sites and then to rely on knowledgeable local intermediaries to identify cases in each selected site. Depending on how this is done, however, the identified cases are likely to be skewed in varying degrees towards ones in which the adult child died in the same locality as the parents resided. The sample then would under-represent parents whose child died away from the parental community since intermediaries would probably be less aware of such cases. Parents in this latter situation are less likely to have been heavily involved in caregiving or to have lived close by to their deceased adult child than in the former situation in which the child died in the parental community. The impact of the illness and death are likely to differ dramatically between these two situations. We discuss this problem at some length below in connection with our research in Thailand.

An alternative approach is to conduct a general household survey to identify cases. In low prevalence settings, locating AIDS parents through a general sample of households is likely to be difficult due to the

rarity of the event. In high prevalence contexts, case density may be sufficient for a random sampling of households to encounter adequate numbers to be practical. Also, because it would be based on a random sample, this approach would theoretically include appropriate proportions of both parents whose child died locally and those whose child died elsewhere. However, to yield representative information, such an approach also requires that the parents contacted be willing to admit that they had experienced the loss of an adult child, to provide sufficient information to determine if AIDS was the cause of death, to be interviewed about it, and to respond accurately to questions asked. More likely, differentials in willingness to be interviewed and in openness about relevant issues among AIDS parents would be related to the outcome variables of interest and thus lead to biased results. For example, parents who were involved with caregiving and living arrangements might be more willing to admit the loss of an adult child to AIDS and to be interviewed about it than those who were estranged from their deceased child or otherwise were less involved. It is also possible that the degree of involvement with caregiving and support by parents would be related to the probability of how easy it would be to find parents at home (and thus to be interviewed). For example, parents who migrate temporarily for seasonal or short-term work will be missed more frequently in such a survey. At the same time, such parents may also be less likely to have been involved with caregiving and living arrangements of their AIDS afflicted adult child.

#### *Developing sensitive instruments*

Some potential impacts are more difficult to assess than others. For example, loss of income can be fairly straightforward to calculate from information on wages and the amount of time spent away from work. Some health impacts will also be quite easy to link to the caregiving experience, e.g., a strained back resulting from lifting the ill adult child. Other impacts of interest can be fairly subtle and not easily measured with a short and easily quantifiable question or two, but are potentially very consequential for the well being of the older parent. For example, negative community reaction might be anticipated and imagined in some cases but in fact not at all intended by neighbors. Depression, social isolation, and anxiety certainly have the potential to decrease the quality of life for the caregiver, but sensitive and culturally relevant measurement tools are often not available in the settings where this type of research is needed most.

#### *Ensuring confidentiality*

Another challenge, especially given the emotional and social sensitivity of the issues being addressed, is ensuring and maintaining the confidentiality of the information collected and convincing potential respondents that this will be the case. The problem of ensuring confidentiality is further complicated in cultural settings where such a concept is relatively foreign or at least not especially salient for the general population. Another key challenge is to devise appropriate ways of conveying these concerns to locals involved in the data collection process, especially those who act as informants and intermediaries, without offending or perplexing them (Booyesen and Arntz 2003).

### **III. Examples of Data Collection Strategies**

Because of the many obstacles to research on the situation of AIDS parents, any single specific method will likely involve compromises that bias results in one way or another. Our approach to this problem is to follow a multi-method approach that allows results to be compared across different methods. Interpretation of findings can take into account the likely biases operating within each in order to arrive at reasonable conclusions. We collected both quantitative and qualitative data through alternative methodological approaches. Our two most extensive sources of quantitative data on the situation of AIDS parents were 1) interviews with key informants about individual AIDS cases and their families and 2) direct survey interviews with AIDS affected and non-AIDS affected parents. More limited quantitative information was also gathered through assisted self-administered questionnaires to persons living with

HIV/AIDS and extraction of information from applications for welfare assistance related to AIDS.<sup>2</sup> Our primary source of qualitative data was a series of open-ended interviews with AIDS parents although we also attempted to derive some qualitative data from the interviews with key informants. Table 1 summarizes some of the main features of the methods we used in Thailand to collect data on the situation of AIDS parents. We now turn to describing each approach in some detail.

### *A key informant approach*

One obvious way to minimize problems associated with the sensitive and emotional nature of the subject matter related to losing an adult child to AIDS is to interview knowledgeable key informants rather than AIDS parents themselves. In our Thai project, we collected individual data through interviews with key informants. For this component, cases consisted of adults who were currently living with AIDS or had died of the disease in a particular locality regardless of where their parents resided or if any parent was still alive. However, since the set of questions included queries about the parents of the case, data on parents are also generated by this approach.

Our key informant study covered a total of 85 different local sites including ones in Bangkok, the major city in Thailand, and in 8 provinces (out of 75) outside of Bangkok. The provinces were purposively selected to ensure geographical diversity. We chose at least one province from each of Thailand's four major regions and included both rural and urban sites in each province. Within each region, however, we chose provinces with relatively high AIDS levels for the region in order to maximize the number of cases that would be identified at any individual site. Nevertheless, because of sharp regional variation in the level of the epidemic, the selected provinces differed considerably in HIV prevalence. For example, for the period 1991-98 the average percent of military recruits from the selected provinces who were HIV positive ranged from 2 to 9 percent.

Thailand has an extensive public health system under the combined jurisdiction of the Ministry of Public Health, municipal governments, and the Bangkok Metropolitan Administration. This system operates at the provincial, district and sub-district level and also includes an extensive network of community health volunteers. In order to identify key informants and gain permission to interview them, we operated largely through this system. For most rural sites, informants were staff of sub-district health centers, the lowest level service facility in the public health system. The particular health stations were chosen in consultation with the AIDS section of the provincial health office. In choosing local sites, we instructed our contacts to select ones where at least one staff member was either a local person or in place long enough to know the community well and where it was known or likely that there had been local cases of AIDS. Thus the local sites were also purposively selected. A typical center was responsible for a median of 1100 households (with 80 percent falling between 300 to 2500). Usually health station staff were able to provide sufficient information on their own. Occasionally, when the staff felt their knowledge of local cases was insufficient, they referred us to village health volunteers who were typically assigned to neighborhoods of 10-20 households.

Overall, a key informant's awareness about the existence of AIDS cases derived from multiple sources including death registers (where they existed), notification of HIV+ status from higher level facilities

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<sup>2</sup> Our project also included other components: a survey of younger and older adults regarding knowledge and attitudes related to AIDS; focus groups and open-ended interviews with health providers at different levels of the health system; open-ended interviews with older unmarried men regarding sexuality and risk behavior. We do not discuss these components in the present paper because they were designed primarily to address issues other than the epidemic's impact on AIDS parents. Reports describing the first of these components are available elsewhere (Imem et al. 2001). Description and analysis of the last two components are currently in progress.

(which occurred only in some places), visits to the health station by the person with AIDS or their relatives, home visits, reports of community health volunteers, and funerals. For the 60 percent of the rural sites that maintained registers of deaths, we asked informants to review those registers case by case to help identify AIDS-related deaths. We explicitly told them to include any cases they were confident had died of AIDS regardless of what cause was stated in the register.<sup>3</sup> We also probed about the completeness of the death register and asked them to identify any AIDS deaths that were not recorded. In sites without death registers, informants relied on memory. To assist them in this task, we asked them to think first about cases in each of the individual subdivisions of their area of jurisdiction (of which there were typically 5-10) on a one-by-one basis and to note down the names as they did so. Only after completing this exercise did we ask informants to provide details on any particular case. This was a useful procedure to systematically jog their memory and keep them focused on identifying the full set of cases. We found that most registers were fairly complete but the information on cause of death was often of dubious value.

Given the different structure of the public health system in urban areas, especially the usual lack of local health service centers equivalent to sub-district health stations, and the greater anonymity of urban settings, we drew urban informants from more varied sources. Both for provincial towns and Bangkok, the corps of urban neighborhood health volunteers was the most important. We also included some community leaders in both settings. In provincial urban areas we occasionally drew on welfare workers, home visiting nurses, and health personnel in local hospitals. Both in Bangkok and provincial urban towns, officials at higher level health offices acted as intermediaries in arranging our contact with the informants for local sites. Generally any particular urban sample site covered far fewer households than a typical rural sample site.

All interviews were conducted by the principal investigators. To keep interview length manageable in sites with many cases, we usually limited the number of cases per site for which information was requested to a maximum of 20 who died locally of AIDS and 5 who were currently symptomatic and living in the community. If the potential cases exceeded our limit, we gave precedence to those who died most recently and to those for whom the informant felt most confident in the information being requested. In the vast majority (over four-fifths) of sites this limit was not reached and thus, in those sites, we collected information on all identified cases.

For each case selected, informants were asked to provide a set of basic information: age, sex, marital status, existence of dependent children, living status of parents at time of illness, if and how long the person lived with a parent, change of residence during illness, and who provided care. For a subset of up to six cases that the key informant knew best, we also asked a supplemental set of questions about economic status, burdens of caregiving, financial arrangements, community reaction, economic impact on the family and specifically on the parents, and ages, health and location of parents. Both sets of information were recorded on pre-coded forms specifically designed for the purpose.<sup>4</sup> In total, key informant interviews yielded basic information on 963 adult cases (768 who were deceased; 195 who were living with HIV/AIDS). More detailed supplemental information was collected for a subset of 285 of these cases, more than 90 percent of whom had already died. In addition, some community level information about the AIDS situation in a locality was solicited for each of the 85 sites.

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<sup>3</sup> The registers were usually informal and did not follow any set format. In some cases in areas of high HIV prevalence separate registers were kept especially for persons thought to die of AIDS. In a few, official copies of death certificates were available.

<sup>4</sup> The forms are reproduced in Knodel, Saengtienchai, Im-em, and VanLandingham 2000.

We tape recorded the interviews with the key informants both to enable us to later check on the information contained in the forms if questions arose during data editing and entry and to capture any elaborations informants offered in comments they made during the interview which bore on topics relevant to our research. Respondents also sometimes cited interesting examples to illustrate their answer to a particular question. We selectively transcribed comments from the tapes for possible qualitative analysis.

### *Direct interviews with parents*

Even under the most favorable circumstances, key informants can be expected to have limited knowledge of any particular AIDS case and only impressionistic information about the impact on family members. Parents themselves are clearly in a far better position to provide more detailed and accurate information about their own situation and that of their AIDS afflicted son or daughter. Thus they would seem to be a preferred source of data provided they are willing to be interviewed and to be open about the issues of interest. In our Thai project we took two approaches to direct interviews with parents. We first conducted open-ended interviews with a small number of AIDS parents to provide data for qualitative analysis. Later we conducted a survey with a structured questionnaire that covered a much larger sample of AIDS parents and included a comparison group of non-AIDS parents to provide data for quantitative analysis.

Open-ended interviews with AIDS parents. At the start of our research in Thailand we were in doubt about the logistical feasibility of conducting a survey of AIDS parents because of uncertainty about how we would identify sufficient cases and about their willingness to be interviewed. We thus started with the key informant approach just described above to get quantitative estimates and with a small number of open-ended interviews with AIDS parents who had been involved with caregiving to an adult child with AIDS to yield more detailed insights. We anticipated that such a direct open-ended approach would not only contribute to a deeper understanding of the situation faced by AIDS parents but also reveal the range and nature of issues that might be explored more systematically with a subsequent survey, should we determine that a survey was feasible.

In total we conducted 20 open-ended interviews with parents of adult children who died or were ill from AIDS. The cases were situated in Bangkok, in two relatively high prevalence provinces, and in one moderate prevalence province. In addition to geographical diversity, the cases varied fairly widely in their socioeconomic level. None of the parents had been active in AIDS advocacy groups and in almost all cases their deceased child had likely acquired AIDS through heterosexual transmission, the predominant mode in Thailand and most of the rest of the world. In these latter two respects, our cases stand in contrast to those typically represented by the limited qualitative research on AIDS parents in the US (e.g. Brabant 1994; Dane 1991; Gregory and Longman 1992; Longman 1995; Peabody 1986). Also significantly, in none of the cases we interviewed did the deceased sons or daughters receive effective treatment for HIV with anti-retroviral medicines as would now be typical of cases in the US but not yet in the vast majority of developing countries.

Local community leaders and staff of a relevant NGO in Bangkok and local government health station personnel in the other three provinces acted as intermediaries in identifying potential respondents and arranging for interviews. At the time of interview, we explicitly reminded interviewees that we wanted to discuss the loss of their adult child and confirmed their willingness to talk about it with us. Neither names nor addresses were recorded to maintain confidentiality. We purposely avoided referring to AIDS in the interview unless the respondent freely admitted AIDS as the cause of the adult child's death. In two of the interviews, respondents did not admit, and perhaps genuinely did not believe, that AIDS was the source of death, although our intermediaries made clear such was the case (and the symptoms described by the respondents were consistent with this). However, to facilitate these interviews, questions were rephrased in terms of caring for and losing an adult child to a prolonged illness without mentioning AIDS.

The interviews followed a common set of guidelines covering numerous issues: caregiving, health beliefs and knowledge related to AIDS, expenses during the illness and their impact on the respondents, how expenses were financed, the role the deceased child had played in the family economy, fostering of grand children left behind by the deceased, community reaction, and emotional reactions and support.<sup>5</sup> Appointments were made in advance and interviews were conducted in a conversational style, usually at the respondent's home to promote a private and relaxed atmosphere. Interviews typically lasted about two hours although they varied depending on the relevance of some issues to the case and how well the respondents could express themselves. If possible, we tried to involve both parents in the interview. Two of the Thai principal investigators conducted the interviews themselves. In the two cases in which respondents did not admit that AIDS was the source of their child's death, questions about beliefs and knowledge regarding AIDS and community reaction were purposely omitted. Occasionally reminders of the deceased child around the house, such as the child's picture, a funeral urn with the child's ashes, or the room or corner where the child lay during the terminal stage of illness, evoked emotional reactions as the interview proceeded. At such moments, the interviewers would express sympathy and pause to allow the interviewee to recover. While the interviews were stressful at times for some parents, our overall impression was that most welcomed our interest in their situation and the opportunity to talk about their experiences with a sympathetic and interested listener.

The interviews were tape recorded (after asking permission of the respondent), fully transcribed in Thai and translated into English. Both the Thai and English transcripts were used in the analysis. We coded transcript text segments in terms of topics and categories of interest and utilized a software program (The Ethnograph) to expedite the retrieval of relevant segments for systematic topical review (Seidel 1998; Knodel 1993).

Direct interview survey. While open-ended interviews can yield a wealth of insights into the lives of AIDS parents, the small number of cases that can be adequately analyzed using a qualitative approach and the purposive nature of the sample do not lend themselves to providing a reliable sense of how common particular circumstances are. To achieve this goal, systematically collected data suitable for quantitative analysis from a sizeable sample are required. In addition, it is important to base such a survey on either a generally representative sample or at least to be able to determine the limits of the population for which it can be considered reasonably representative.

Our experience from both the key informant and open-ended interviews encouraged us to carry out a direct interview survey using a structured questionnaire. In addition to interviewing AIDS parents, we decided to include an equivalent sample of non-AIDS parents to permit comparisons. Because of the lack of precedents for such a survey, considerable effort was required to develop an appropriate questionnaire. The open-ended interviews gave a good basis for a start. Nevertheless, we needed to devote considerable time and collective team effort, involving multiple stages of pre-testing, to develop our questionnaire. The final version included sections dealing with household structure and characteristics of members, socioeconomic background, characteristics of all living children, and measures of well-being now and in the recent past that were asked of both AIDS and non-AIDS parents. Additional sections that were directed only to AIDS parents asked about details concerning the deceased child and his or her illness, caregiving arrangements and their consequences for the parents during the child's illness, economic effects associated with their child's death, and community reaction.<sup>6</sup>

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<sup>5</sup> The guidelines are reproduced in Saengtienchai and Knodel 2001 .

<sup>6</sup> The questionnaire is reproduced in Knodel et al. 2002 .

Our selection of sites for the survey involved two stages. First we purposively chose three provinces among those that had been included in the key informant study. This helped to ensure some consistency in coverage and allowed us to take advantage of contacts we had already established in the provincial and local health system. However, to ensure some breadth of coverage, each of the three provinces were from different sub-regions. We also incorporated some epidemiological variation by selecting two provinces with high HIV prevalence and one with a much more moderate level.

The second stage involved the selection of localities within each province. To do this, we contacted either the provincial or district health office, explained the purpose of our survey, and asked them to assist in the selection of tentative sites. For the purpose of our survey, a site generally corresponded to the areas of responsibility of sub-district government health centers in rural areas and of municipality community health stations in provincial towns. As with the key informant study, we specified that the site should have health personnel who had been at the site sufficiently long to know who died of AIDS over the last several years. We also asked that both rural and urban sites be included.<sup>7</sup> Although the three provinces were also included in the key informant component, only a few of the local sites chosen were the same. We made pre-survey visits to judge the suitability of each site and to list potentially eligible cases for interview. Because we attempted to interview roughly the same number of cases per province, we needed to include substantially more sites in the moderate prevalence province than in the other two to achieve this.

In order to avoid the need for self-identification among AIDS parents, we relied on local health personnel at each site to serve as intermediaries in identifying locally residing parents who lost an adult child to AIDS (as well as to identify appropriate comparison cases of non-AIDS parents). During the pre-survey visit to each site, we asked the intermediaries to identify all adults who died of AIDS locally during the past three years following similar procedures to those used in the key informant study to facilitate this step. At some sites, the health center staff also asked village health volunteers to assist in the identification of AIDS deaths. Once those who died of AIDS were identified, we asked the intermediaries to indicate which ones had parents who lived locally. In order to complete the listing of AIDS parents in the locality, we next asked the intermediaries to think of any local parents who had a child that died of AIDS elsewhere (i.e. outside the locality). This task proved much more difficult for them since such deaths are less likely to be known to local health personnel than are local deaths. As a result, the list of locally residing AIDS parents disproportionately represented those whose deceased son or daughter either had lived locally even before becoming ill or who became ill elsewhere but returned to the parental community before dying. We discuss the implications of this below.

After compiling as complete a list as possible of AIDS parents in the locality, we asked intermediaries to provide basic information needed to make a final selection for interview and to guide the selection of comparable cases of non-AIDS parents. This information included the month and year when the child died, approximate ages, marital status, and economic status of the parents themselves, and a judgement by the intermediary as to whether the parents might be willing and available to be interviewed. We generally limited selection of parents to be interviewed to those whose adult child died of AIDS at least 6 months prior to the survey (to allow for sufficient time for some consequences to be evident) 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 fieldwork. We also eliminated a small number of cases

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<sup>7</sup> However this turned out to be feasible only for two provinces. In the third province, after ascertaining that it would be unlikely for us to find intermediaries who could identify cases at a local community level within the main city (which is far larger than the provincial towns in the other two provinces), we decided to only include rural areas but to purposively select sites in different districts that ranged in distance from being quite close to being relatively far from the city.

from consideration that the intermediary believed would not be available or would not agree to an interview.

Within the remaining group, we usually attempted to interview all cases identified. The exceptions were in several sites in one high prevalence province where the number of potential cases was too large to cover given our survey schedule. At these sites, we interviewed a systematic random sample of those identified. 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. 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 at least one living adult child but who had not experienced any recent death among their children. Some were able to do this during the pre-survey visit while others needed more time. In the latter situation, the list of non-AIDS parents was given to us when we returned to conduct the actual survey a week or so later.

Prior to the arrival of the team of interviewers, we asked the intermediaries to contact the persons we selected and request permission for an interview. The actual extent to which these instructions were followed varied and in some sites, permission to be interviewed was only asked at the time of the survey. In order to prepare AIDS parents who were potential respondents for the survey, we asked intermediaries and interviewers to explain that the survey concerned the consequences of suffering the loss of an adult child without mentioning AIDS specifically. In addition, no question in the survey specifically referred to AIDS as the cause of death. Intermediaries and interviewers were also told to stress that the interview was voluntary, that all interviews were anonymous and confidential, and that no identifying information would be recorded. This avoidance of referring to AIDS and assurance 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.

The interview teams were drawn either from a pool of experienced interviewers used in previous projects or were current students, most of whom were studying nursing. Interviewer training stressed the sensitive nature of the subject matter in the case of AIDS parents and the need to adopt a sympathetic manner during the interview. If the respondent appeared emotional or upset at any point, the interviewer was to pause and allow the respondent to recover before continuing. One or more principal investigators accompanied the teams at all times. Interviewers were monitored by supervisory staff to ensure that interviewers dealt sensitively with AIDS parents. Only one interviewer seemed not adept in this and was subsequently assigned only to interview non-AIDS parents. After each day of interviewing, we held debriefing sessions with the team of interviewers to identify problems and share experiences. Techniques for dealing with respondents who became emotional during the interview were reviewed at these times. Interviewers were asked to note at the end of each interview if the interview had been emotional for the respondent. They judged that almost half of the AIDS parents found the interview was at least somewhat emotional. This included 12 percent who found it 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.

The many steps involved in the identification and selection of potential cases for interview and a lack of complete accounting at each step of the outcomes made it impractical to calculate a precise response rate for the survey. In most sites, however, it is clear that the large majority of potential respondents who were initially identified agreed to be interviewed.<sup>8</sup> In total, we conducted 394 interviews with parents of

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<sup>8</sup> For a fuller discussion of the difficulties of ascertaining response rates see Knodel et al. 2002.

persons who had died of AIDS within the prior three years, and 376 with the comparison group of parents of similar ages and backgrounds who did not experience any recent death among their children. If both parents were alive and living together, some questions were asked about each parent separately (generating information for 649 AIDS parents and 621 non-AIDS parents).

#### *Other data collection approaches*

Besides the key informant study and direct interview survey, more limited quantitative information was also gathered through two other approaches: assisted self-administered questionnaires to persons living with HIV/AIDS (PLWHA) and extraction of information from welfare applications.

PLWHA group member data. Although there is a national system for registering information about persons diagnosed as HIV positive that serves as a basis for official statistical reports, it is anonymous and cannot serve as the basis for drawing a probability sample of PLWHA. Thus in order to collect data from persons living with HIV/AIDS, we took advantage of the existence of organized PLWHA support groups in Thailand to identify and recruit respondents for the study. Choices of PLWHA groups were based on personal contacts with leaders of these groups or colleagues who had contact with them. Although our sampling procedure is clearly unrepresentative of PLWHA generally, and even those who are members of PLWHA groups, it was a practical way to gain access to PLWHA in Thailand who are still well enough to participate in such a project.

We designed the questionnaires for PLWHA to be suitable for self-administration. The questions covered a wide range of topics including symptoms, medical treatments and social reactions of others. Several questions dealing with caregiving issues and past and planned residential change in relation to the illness were particularly relevant for the study of AIDS parents. In total, completed questionnaires were obtained from 425 PLWHA drawn from members of groups in Bangkok, a province adjacent to Bangkok, and three higher prevalence provinces in northern Thailand.<sup>9</sup> In most cases assistance was provided during the process of filling out the questionnaire. Typically a representative of our project explained the questionnaire to an assembled group and together with assistants answered questions and helped clarify questions if respondents had problems. Some respondents answered the questionnaire in a more individual context when visiting a PLWHA group's office or going for support service. Even under these circumstances, however, our contact at the group or a research assistant was usually present to answer any questions that might arise.

Welfare applicant information. Information on living arrangements of persons applying for public welfare designated specifically for persons diagnosed as having AIDS and their families was extracted from applications in six of the provinces in which we carried out the key informant study. The number of applications available for inspection varied greatly by province. In most provinces, we were able to examine all applications for data extraction. However in one province with an unusually large number, we stratified the applications by district and systematically sampled from each district in proportion to the number of AIDS cases per district as reported in the official AIDS statistics for that province.

Although the application form includes an item asking for a list of persons with whom the applicant currently lives, the information provided was sometimes missing and, even when present on the application, might not be accurate. Of particular concern was that the list of current household members might refer to those who are legally registered as residents of the household rather than those who are actually living there at the time of the application. In Thailand, everyone is required to be registered in a

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<sup>9</sup> For details of the methodology of this component of our project including a copy of the complete questionnaire see VanLandingham and Im-em 2001.

household and indeed a photocopy of the official household registration form for the household in which the applicant is legally registered had to be submitted with the welfare application. In reality, it is not uncommon for Thais who move out of their household of origin to retain their registration in their former household rather than register in a new household. Thus official household membership as indicated by the registration forms may not accurately represent current actual residents. To minimize this problem in the welfare application data we analyzed, we excluded from our analysis most applications that lacked separate information on the item requesting a list of persons with whom the applicant coresided. In addition, we performed a variety of complex consistency checks between information in the official household registration form (which was attached to the welfare applications) and other information written on the applications (including the list of coresident persons). This permitted us to eliminate most cases in which the information on actual living arrangements was likely inaccurate. The final sample consisted of a total of 826 applicants aged between 15 and 49 who applied for assistance between 1996 and 1999.

#### **IV. Comparisons of Approaches**

Given that there are many differences among the approaches described above, it is useful to consider the strengths and weaknesses of each and to compare them as systematically as possible in order to shed light on potential biases that may characterize the findings they yield. Since the open-ended interviews were intended to be only illustrative and were based on a very small number of cases, we exclude them from comparisons of a quantitative nature. We start our comparisons by examining the demographic characteristics of the samples we obtained. We then turn to comparisons of findings on the several issues that can shed light on some of the biases inherent to a particular approach.

##### *Sample characteristics*

None of the four approaches to quantitative data collection just described was designed to be nationally or even locally representative in any statistical sense. Nevertheless, it is instructive to compare the basic demographic characteristics of our samples with what would be expected from a nationally representative sample. To do this we draw on the national registry of AIDS cases maintained by the Ministry of Public Health that is based primarily on cases diagnosed at government hospitals. While this registry is likely to selectively omit cases that are motivated not to be included, these data are the only national source of direct relevance to our sample. Table 2 shows these comparisons.

The sex distributions of both the cases reported by key informants and the deceased children of the AIDS parents included in the direct interview survey are rather similar to that of nationally registered AIDS cases reported for 1997-98.<sup>10</sup> However, women are clearly over-represented among both the PLWHA group members and the welfare applicants, especially the former. Others have noted the predominance of women, primarily HIV infected widows of men who had died of AIDS, in PLWHA groups in Thailand (Muecke 2001). Also some of the welfare programs from which we extracted data intentionally targeted women. In contrast, the age distributions of PLWHA in all four of our samples are rather similar to that of nationally reported AIDS cases. The most apparent difference is the lower proportion of older PLWHA among the deceased adult children reported by AIDS parents in the direct interview survey. This reflects the lower likelihood that older PLWHA have a living parent (a prerequisite to be reported on in the sample of AIDS parents).

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<sup>10</sup> We focus on reported cases for 1997-99 since our samples are skewed towards recent cases reflecting the selection process and the timing of fieldwork.

The marital status distribution of the key informant sample and the deceased children of the AIDS parents covered by the direct interview survey are reasonably consistent with that of nationally reported AIDS cases. Most notably, married persons are clearly the most common category followed by single persons in the AIDS registry and both samples. Nevertheless, there are some discrepancies in the shares of those who are divorced and widowed. Much greater discrepancies are apparent for PLWHA group members and welfare applicants. Both, but especially the former, include far higher proportions of widowed PLWHA than is the case nationally. This is related to the disproportionate number of women in the two samples, given that most women become infected through marital sex with their husbands who were infected earlier and thus typically die first.

Information on the rural-urban distribution is not available either for the registered AIDS cases or for the welfare cases. However, we note that approximately two thirds of the adult cases reported by the key informants and the PLWHA group members are drawn from rural settings. This closely resembles that of the national population in general. In the case of the AIDS parents, we do not have information on the rural-urban distribution of the deceased adult children, but 82 percent of the parents were living in rural areas, giving a substantial rural emphasis to the sample. Unlike the other demographic characteristics described above, the rural-urban distribution of our sample is a function of the deliberate site selection incorporated into our research design.

In brief, these comparisons suggest that the sample of cases reported by the key informants and by AIDS parents in the direct interview survey are reasonably similar to the national registry of AIDS cases with respect to their age, sex, and marital status distributions. In contrast, welfare applicants and, to an even greater extent, the PLWHA group members differ considerably from the national caseload in their sex and marital status distributions. These differences in demographic characteristics are likely to affect the nature and extent of biases in the results that the different approaches yield. Of course, even those approaches that yielded samples that appear typical with respect to the demographic characteristics examined may still be biased in other ways that are independent of these characteristics but related to our outcome variables.

### *Comparison of selected results*

Living arrangements. As noted above, adults with AIDS who eventually return to a parental home before dying often do so only after symptoms are advanced and death is imminent. Thus, unless the person with AIDS has already died, the full extent that adult children end up eventually living with and being cared for by a parent will be underestimated. For this reason, samples of PLWHA from support group members, from welfare applicants, or as reported by key informants will underestimate the percent of terminal stage residence in parental homes. The extent of this bias is likely greatest for the PWA group members since they are all still well enough to attend meetings and fill out questionnaires, and least for welfare applicants who can have their application filled out by a proxy and, to qualify for welfare, are typically required to be certified by a medical doctor as having advanced symptoms. Currently symptomatic cases reported by the key informant are likely to be intermediate since most have displayed symptoms noticeable enough to be recognized as characterizing AIDS by the informant or by others who report to informants but not necessarily to be at a very advanced stage.

Figure 1 compares the percent of adults aged 20-49 who reside with a parent in the general population with that of the samples of persons with HIV/AIDS revealed by our various approaches to data collection. Information for the general population is available from a 1994 general household survey conducted by the National Statistical Office and serves as a base level for comparison. As anticipated, the AIDS cases from each of the sources are clearly more likely to live in the same household with a parent than are persons 20-49 in the general population. This undoubtedly reflects the moves by persons with AIDS when they become ill to live with parents (or have parents join them). Moreover, the pattern of differences

among the various samples of AIDS cases is also consistent with this process. PLWHA group members are likely at the least advanced stage of illness of the samples and indeed appear to be least likely to be living with a parent while those who died of AIDS as reported by key informants already passed through the terminal stage and thus reflect the full extent of return to parental homes as a result of illness.<sup>11</sup>

These results underscore the importance of taking into account the time frame in which impacts on AIDS parents are being evaluated. Clearly, the likelihood of parental involvement in living arrangements and caregiving increases as the illness of an adult son or daughter progresses. Previous analysis of the key informant and direct interview data indicate that between a third and two-fifths of adult children with AIDS who were cared for by parents at the terminal stage had returned home from elsewhere (Knodel and VanLandingham 2003). That they return at a late stage of illness is evidenced by findings of the direct interview survey indicating that almost a fifth of the adult children died within a month and almost half died within three months of returning home (Knodel and Saengtienchai 2002).

Parental caregiving. Comparisons of estimates of the extent that parents give care to their adult children who become ill with AIDS illustrate both how the time frame within the progression for infection to death, and how differences in the extent samples are skewed towards certain types of cases, impacts results. Such comparisons need to be made cautiously given the differences in geographical coverage and background demographic characteristics of the samples. Still if the approaches have substantially different inherent implications for findings, these should still stand out in such comparisons.

Table 3 compares estimates of parental caregiving derived from the key informant, direct interview survey, and PLWHA group approaches to data collection. Two sets of results are shown. The first is based on all adult HIV/AIDS cases while the second is conditioned on cases that have at least one living parent. Note that results from the direct interview survey with AIDS parents necessarily are limited to the later and thus are not included in the first set. Also note that for the second set, the key informant results are adjusted for the small minority of cases for which the key informant did not know if any parent was alive.<sup>12</sup> For each set, two measures of parental caregiving are shown. The first is whether a parent provided any personal care and the second refers to whether a parent was considered to be a main caregiver. The measures of main caregivers differ slightly among the sources but not sufficiently to have much effect on the results.<sup>13</sup>

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<sup>11</sup> The results shown in Figure 1 partially reflect differences in the age and sex distributions of the various samples. However, the pattern of differences remains the same when results are standardized for age using the age distribution of AIDS cases for the years 1997-1999 as reported in the national AIDS registry as the standard (Knodel and VanLandingham 2003).

<sup>12</sup> In 8 percent of cases the informant was uncertain if a parent was alive (typically involving cases who were non-local spouses of local persons). In many of these cases the parents are likely to be alive. However since informants are probably more likely to know of living than dead parents (e.g., the parents may have visited the community), these unknown cases are probably skewed towards persons with deceased parents. Thus in the calculations we assume that the proportion with a living parent is two-thirds that of the equivalent 5-year age group based on cases for whom the parents' living status is known. Given the small percentage of cases involved, results are only minimally affected by this assumption.

<sup>13</sup> In both the key informant and direct survey interviews with AIDS parents, but not in the PLWHA survey, more than one person could be designated as a main caregiver. However, only in 8 percent of cases in the key informant data and 12 percent in the direct interview in which a parent was designated a main caregiver was another person besides a parent so designated. In fact, 3.5 percent of respondents in the PLWHA group also indicated more than one main caregiver even though questionnaire instructions clearly said to choose only one. However, the specific responses marked were not coded and thus these cases are excluded from the base used to calculate the results shown in Table 3.

Caregiving in general typically occurs only after the illness has progressed far enough that self-care is no longer adequate by itself. Moreover in the case of persons who first become symptomatic away from their parental home, parental caregiving can occur only after the ill adult child returns to their parents or the parents go to where the ill adult child is living. Thus, all else equal, the further along in the progression of the illness, the higher the level of parental caregiving that will be indicated. This is clearly evident from the substantially lower percent of parental caregiving reported by key informants for currently symptomatic versus deceased cases. It also certainly acts to depress the level of parental caregiving reported by PLWHA group members. Interestingly the reported percentage for which a parent provide any caregiving is higher among the PLWHA than for the currently symptomatic as reported by key informants while the reverse is true for parents as main caregivers. In fact, based on our assumption that the PLWHA group members were probably less advanced in their stage of illness than the currently symptomatic cases reported by key informants (as discussed above when interpreting the percentage living with a parent), we would expect higher parental levels of both any caregiving and main caregiving among the latter. While not too much can be made of this given the very different natures of the samples as discussed above, it might also reflect more inherent differences in the approaches. In particular, key informants may be more aware of more conspicuous behaviors of AIDS parents, such as major caregiving, but less aware of less obvious behavior such as supplemental caregiving. In contrast, PLWHA will be fully informed of both aspects of caregiving.

The substantially higher levels of parental caregiving by the terminal stage of illness that is indicated for deceased children by direct interviews with AIDS parents compared to reports by key informants (as shown in the set of results conditioned on cases with a living parent) likely reflects differences in selectivities among the two samples. As noted, the direct interview sample is skewed towards cases in which the adult child is in the parental locality at the time of death. For example, 82 percent of adult children who died as reported by AIDS parents lived with the parents at the terminal stage of illness. This is far higher than the 70 percent of cases with living parents as estimated by the key informant study (after adjusting for cases for whom it was unknown if a parent was alive). This will bias estimates of parental caregiving upwards since they are more likely to have provided care (and probably be more vulnerable to some potentially adverse economic and social impacts) than are parents of those who die away from the parental community. In contrast, the key informant study referred to all adults in the local community who were currently symptomatic or who had died of AIDS, regardless of whether their parents lived locally or elsewhere. Also unlike the direct interview survey, inclusion of a case did not depend on the willingness of a parent to be interviewed. This could play a role as well if parents who were less involved in caregiving were also more reluctant to grant an interview. We note, however, that although the overall direct interview sample appears skewed towards parents who were involved in caregiving, the sample may still be reasonably representative of this large subset of caregiving parents.

### *Maintaining confidentiality*

Finally it is of interest to comment on problems associated with maintaining confidentiality in the different approaches. We note that in all approaches, names of individual cases were not recorded and thus all data are in effect anonymous. However, in the actual process of data collection problems could arise. This appeared to be more of an issue with the key informant study and direct interview survey, both of which involved substantial and active roles of local personnel, than in the other three approaches. Difficulties for maintaining confidentiality when using local persons in fieldwork is clearly not unique to Thailand and has been noted as a general problem for AIDS impact research (Booyesen and Arntz 2003).

In the key informant component, we tried to convey our concern about confidentiality to key informants before the start of the interview. Indeed, some informants spontaneously expressed concerns about confidentiality themselves and tried to arrange for maximum privacy during the interview. Others, however, seemed unconcerned and sometimes would shout questions about cases by name to other staff

when health center clients were within earshot. Thus occasionally we had to remind informants of our concern about confidentiality during the interviews to reduce repeated breaches. We note, however, that while such incidents in principle violate confidentiality, within a typical rural Thai community in practice the vast majority of local residents (and hence health center clients) would already be aware of anyone who was currently symptomatic or who had died of AIDS and thus new information was probably not being conveyed. This likely underlies what at times appeared to be casual attitude about such matters among our informants.

Some of the same problems occurred during the initial stage of the direct interview survey when we were asking intermediaries to identify cases. However, it was less common because, unlike in the key informant study, we were asking very minimal information about each case and the intermediary had less need to ask others for assistance. However, breaches of confidentiality could also occur following identification of the AIDS parents and controls slated for interview. As noted, health center staff used village health volunteers to contact potential respondents to make appointments for the direct interviews. Although we stressed to the intermediaries that they should not mention that our research was focusing on effects of adult children dying of AIDS, some may still have indicated this to other staff or to the village health volunteers whom they recruited to assist. If so, word may have spread further to others in the village. Thus a visit to a selected AIDS parents' household for an interview could have called attention to their situation. Again, even if such breaches did occur, it seems likely within the context of a rural village that those who observed interviewers entering the homes of respondents, especially if they were neighbors, would almost certainly have already known about the AIDS death. In addition, the fact that we interviewed both AIDS parents and control cases that did not lose a child to AIDS may have blunted this problem.

Maintaining confidentiality during the interview could also be a potential problem although this did not often arise. One reason was that we specifically trained our interviewers to deal with situations in which neighbors might come to listen out of curiosity. Probably most important, interviewers attempted to arrange for a private setting before starting the interview. In addition, when curious onlookers did appear, typically it was at a fairly early stage of the interview when questions dealt with general background information. In actuality, onlookers often quickly lost interest and wandered away by themselves eliminating the need to explicitly ask them to leave. Nevertheless, if an explicit request had to be made, it might have raised curiosity about what the interview was about. Also neighbors may have asked the respondents about the interview after it was completed and placed an AIDS parent respondent in an awkward position. According to both our observations and reports from the interviewers themselves, it was usually possible to conduct interviews in private and, if necessary, to diplomatically discourage onlookers from listening. Having an assistant along for the interview is valuable in many ways, and particularly useful to distract a persistent intruder who is interested in the discussion. Sometimes a simple explanation of the need for privacy will suffice, but in some cases it might be necessary for the assistant to engage the intruder in a general conversation about their health, children, etc., out of earshot of the interview of interest so that it can continue in private.

In the other three approaches, confidentiality issues were usually minimal. In the case of open-ended interviews, the number of cases was small. Our contact person would identify those cases that he or she knew well and did not need to ask others for advice. The actual interview usually involved only one principal investigator going to visit the home of the AIDS parent, an event which would call much less attention to others within a locality than would a whole team of interviewers arriving to conduct a survey throughout the community. In the case of the assisted self-administered questionnaires filled out by PLWHA, maintaining privacy was essentially not an issue. When the questionnaire was filled out in a group setting, all members knew each other anyway and would be aware of their HIV positive status, the reason they were members of the group in the first place. Likewise, the HIV positive status of those PLWHA who filled out questionnaires in individual settings when visiting a support center would also

already be known to any potential observers at the center. Finally, in the case of extracting information from welfare applications, arrangements were made directly with welfare officials and the extraction procedure was carried out by the primary investigators themselves in a private setting.

## V. Lessons Learned

While there is much that distinguishes Thailand from other settings in which AIDS has profound impacts on older parents, many of the methodological challenges we discuss here will have to be faced in other locales as well. We summarize below what we believe to be some key lessons learned from our research conducted in the Thai context that have relevance elsewhere.

*1) The research plan is best developed in successive steps that involve testing feasibility and presumptions as part of the process.*

The relative lack of prior research on the impact of AIDS on the parents of those who become ill and die means that there are few precedents available on which to base a research design. As a result, it will typically be difficult to know in advance the full range of potential data sources that may be available and how to best take advantage of each and how usefully to combine them. In our research, an initial two-week pilot project enabled us to assess the situation as it actually existed in the field. This was critical for our efforts to develop a realistic research plan. For example, only actual field visits to health centers during the pilot phase revealed the potential of local staff as a source of reasonably accurate and sufficiently detailed individual case information. It was at this point we also learned about the existence of welfare assistance applications at provincial welfare offices and were able to determine that they could be a useful, if unconventional, source of information on living arrangements suitable for quantitative analysis that could be extracted at minimum expense.

In addition, we needed to substantially modify our plan during implementation as we continued to learn more about the potential sources and their limitations. For example, one initial goal of our project was to assess the completeness of statistics on older age AIDS cases by comparing information available at local health centers with official statistical records kept at provincial health offices. Only when we actually tried to carry this out did it become apparent that too many difficulties were involved to make this part of our research plan practical. For example, as we visited more health stations once actual fieldwork started, we discovered that many did not have the amount of detail in their records that we had found for the few we visited during the pilot project. In addition, without access to identifying information we were unable to match cases when, as we typically discovered, the numbers of cases from the two sources differed substantially. On a more positive side, only during the course of our interviews with key informants and open-ended interviews with AIDS parents, did it become clear that a survey involving direct interviews with AIDS parents would be possible by using local health personnel as intermediaries to identify and contact potential respondents.

It was also only during implementation that the necessity of having different logistical strategies in rural and urban settings for data collection in our key informant component became evident. Obtaining data efficiently in Bangkok, the only large city in Thailand, was particularly difficult and required considerable experimentation to develop a feasible strategy. One problem in urban settings, and particularly in Bangkok, was the greater anonymity of residents compared to rural areas thus reducing the “coverage” of individual cases that any particular key informant could be expected to know. As a result we had to seek informants at lower levels of aggregation. Our solution was to work largely through the network of health volunteers in organized communities. Hence the number of cases for which any single informant could provide information was much smaller than for the typical rural informant, making data collection less efficient. In addition, because such communities are typically characterized by low to moderate income residents, our urban sample lacks higher income cases.

*2) Substantial involvement of principal researchers in the data collection activities is essential for the success of the overall project.*

The necessity for innovative approaches to data collection combined with the complexity of research incorporating multiple methods means that principal researchers need to be actively involved throughout the data collection process. This is in contrast to many social science research projects in which the involvement of senior research team members is far less demanding in this respect and typically is limited largely to designing the research before fieldwork begins and to analysis of data after its completion, with much of the data collection process being delegated to lower level staff and assistants. Only the key researchers will have sufficient understanding of the project's goals and the substantive issues underlying them to develop the study design. The stepwise approach that we advocate to develop the project components requires the principal researchers to be present during early contacts in the field in order to ensure that their final designs are suitably adapted to the actual situation. Moreover, appropriate methods may also require the substantial involvement of the principal researchers in their implementation.

Of the five particular data collection methods we utilized, it was necessary for the principal researchers to be closely involved in the implementation of all but one, requiring substantial time in the field. Soliciting individual case information from key informants typically involved many on-the-spot decisions about how to proceed at each site. Thus it was important for principal researchers themselves to carry out all key informant interviews. Likewise, although we had prepared general guidelines for the open-ended interviews with AIDS parents, the interviews involved adaptation of the guidelines to the respondent's situation and extensive probing that only a principal researcher was in a position to carry out adequately. Developing a questionnaire for the direct interview survey of AIDS parents (and controls) on the wide range of multi-faceted and sensitive issues of interest was particularly challenging given the absence of an existing workable model. Thus it was essential for the principal researchers to conduct successive pre-testing themselves as we developed and refined the instrument section by section. While the fixed format of the questionnaire made it suitable for teams of interviewers to administer it to respondents, its complex and sensitive nature meant that the principal researchers had to be in charge of the interviewer training and to be present in the field to supervise during the actual survey. Extracting information from welfare applications was more straightforward and assistants could do some of this. Even here, however, judgments were often needed regarding the unanticipated irregularities that frequently were encountered in how the applications were actually filled out, so principal researchers needed to be present during the extraction process. Only the self-administered survey of PLWHA groups did not require involvement of principal researchers beyond construction of the questionnaire, which was purposely designed to be straightforward and readily understandable, although as a result limited in the issues it could address in detail.

*3) Key informants can serve as a valuable source of quantitative data.*

Key informants have often played an important role in anthropological studies and are typically associated with qualitative research. Thus our use of key informants, mainly within the public health system, to provide individual case information suitable for quantitative analysis represents an innovative approach to quantitative data collection. One important limitation of the approach is that the key informants are unlikely to know more than basic information about most cases. Nevertheless, the key informant strategy has several major advantages. First, it provides a means to identify substantial numbers of cases in the absence of registers or other suitable sources. Second, it avoids most problems associated with the sensitivity of the topic, since those being referred to in the information are not directly involved. Third, it is relatively efficient because one interview with a key informant typically produces data for multiple cases.

For this approach to work, researchers need access to informants who are familiar with virtually all AIDS cases in their locality or with at least a representative range of cases, and are willing to provide the information requested. We worked through official government channels to access staff of local health centers (or other appropriate informants). To increase chances that informants we interviewed would be sufficiently familiar with local AIDS cases, we requested sample sites where a local person, or someone who served long enough to know the community well, could act as informant.

A key informant approach clearly carries potential risks. Informants might have selective familiarity with cases in ways that could bias results. For example, they might be more likely to know of cases who had lingering illness and relatively high care needs, who used public rather than private health services, who were longer term residents in the community, or who had greater need of welfare assistance than those in opposite circumstances. To the extent that such selective knowledge of cases exist, they are more likely to affect informants' awareness of persons who are currently ill than those who already had died of AIDS. A death becomes quickly and widely known, especially since funerals are quite public affairs in Thailand as in many countries. In contrast, the onset of illness is more easily concealed or otherwise not necessarily known to many in the community (Aggleton and Warwick 1999; Bryant and Prohmmo 2002.; Danziger 1994). In our experience, identification of currently symptomatic cases was clearly more difficult for key informants than identifying AIDS deaths. Although generally not a problem for our research, in ethnically or religiously diverse societies where shared group identification is strong and barriers to interaction between groups exist, a key informant's familiarity may only be adequate for cases who are of his or her own group.

Clearly, the choice of who serves as key informant is important. Obviously a suitable informant needs to know the local situation well. It is important to make clear the purpose of the research at all levels of contact and especially at the actual sample site. In our experience official heads of selected health centers sometimes assumed it was their bureaucratic responsibility to serve as our source of information, even when their knowledge was limited. More generally, there is typically considerable variation among health station staff in how much or which particular cases they know. Thus, it is useful to have several informants join the interview to improve the completeness of the cases identified and the information provided.

A related observation is that persons who are further from the source of a situation often have misleading impressions derived from anecdotal information about extreme situations that more readily stick in their mind. For example, impressions of provincial health office staff about community reaction did not necessarily correspond to the situation as revealed by persons at lower levels, such as health station staff and village health volunteers, who were closer to the population of interest.

Besides having several staff serve as informants in an interview, there were a number of techniques that can be used to improve the quality of the data being collected. As noted in the description of the key informant component above, it is important to direct the key informant to think systematically about AIDS cases to reduce selectivity in those reported. One way to do this was to have informants review death registers, if available to prompt their memories. When no register is available, informants can be asked to think systematically about AIDS cases in administrative subdivisions of their area of responsibility one by one, rather than for the entire area as a whole all at once. Even if death registers are available they may be incomplete. Thus additional cases may be revealed if informants are also asked to think systematically about cases not in the register. We found it useful to keep the informant focused on case identification before asking for details about any particular case. We also found it helpful to show the informants in advance the forms on which we record case data. This made the process more transparent and alerted informants as to the information that we needed for individual cases. We also tape-recorded the interviews. This proved very helpful during data entry as we could listen to the tape to resolve inconsistencies or omissions in filled out forms.

*4) Local health staff can serve as intermediaries to greatly facilitate the identification and recruitment of respondents for a survey of AIDS parents.*

As noted above, drawing a general household probability sample to find and interview AIDS parents is unlikely to be feasible in most settings. Our experience demonstrates that a practical alternative strategy is to enlist local health staff to act as intermediaries to identify AIDS parents and obtain their agreement to be a respondent in a survey about their experiences. These intermediaries should also be able to identify and arrange interviews with older age parents who could serve as “control” cases for comparison if such a design is desired. The success of this strategy depended on enlisting intermediaries who were in a position to know which parents within the community had lost an adult child to AIDS, to have a means to contact these parents, and to have sufficient trust and respect from potential respondents to solicit agreement to be interviewed. To a large extent, staff of local health centers, with the assistance of their network of village health volunteers, met these criteria. As in the key informant component, it was necessary for us to work through official channels to gain access to and assistance from the intermediaries.

An important weakness of this strategy is the difficulty intermediaries may have in identifying local parents whose adult son or daughter died of AIDS elsewhere. If so, the sample of AIDS parents will be skewed towards those whose child died locally (including ones who returned from elsewhere). These parents tend to be selective of those who were involved in the care and support of their deceased child during the time of illness and probably who are more impacted by the loss in other ways as well. However, since most persons who die of AIDS and have living parents, at least in Thailand, are with their parents at the terminal stage of illness, this approach can at least provide reasonable data for this large subgroup.

As we found, it is likely that any practical strategy for soliciting AIDS parents for a direct interview survey will not produce a probability sample. Under such circumstances, a semi case control design as we followed can partially compensate. This is an approach others have advocated for impact studies more generally (Booyesen and Arntz 2003). Interviews with a control group of non-AIDS parents from the same sample sites, and who are roughly similar to AIDS parents on some basic characteristics, provide a reasonable basis for comparisons since the control group will share some of the same sample biases as the AIDS parents sample. We note, however, that besides choosing controls from the same sample sites, intermediaries found it difficult to juggle more than two conditions simultaneously when finding appropriate controls thus limiting the number of characteristics on which matches between AIDS parents and controls can be made. Also, since the matching needs to be done prior to the survey, accurate information about the relevant characteristics of AIDS and non-AIDS parents needs to be available in advance or error will be introduced into the selection of the control group.

*5) Qualitative data from open-ended interviews can provide rich insights into the circumstances and experiences of AIDS parents.*

Open-ended interviews with AIDS parents yield data for qualitative analysis that can facilitate the understanding of situations that are complicated and for other reasons are not readily captured in a closed-ended question survey format. Using a conversational style allows and indeed encourages interviewees to express and elaborate their views. Such interviews also readily permit probes for clarification or more detail. The style of interview is also suited for building rapport between the interviewer and respondent, a feature that can be particularly important when dealing with sensitive subjects such as the death of an adult child due to AIDS. In addition to serving as the basis for a qualitative analysis in their own right, open-ended interviews can provide helpful guidance for the design of instruments intended for quantitative data collection. Because of the time-intensive nature of qualitative analysis, however, the number of interviews involved is typically small and the results serve mainly an illustrative role. At best they provide only a

very rudimentary and preliminary indication of which themes are more common than others and are not a substitute for broader based systematic quantitative data collection. Yet our experience with the analysis of the qualitative data that we collected regarding AIDS parents clearly confirms the point made by others about the importance of including a qualitative component in AIDS impact studies more generally (Booyesen and Arntz 2003).

Key informant interviews can also serve as a secondary source of qualitative data. Often the key informant makes interesting commentaries during the interview, elaborating on answers beyond what could be noted in the forms or touching on issues of interest beyond the content of the items being asked about. Informants also sometimes describe interesting examples. If the interview is tape recorded, these comments can be extracted and transcribed for analysis. However, our experience serves as a warning that appropriate preparations are needed to successfully exploit key informant interviews intended primarily for quantitative data for this purpose. The main problem is the sheer mass of the amount of tape-recorded material that needed to be sifted through to locate the occasional comments of interest for qualitative analysis (in our case 85 separate interviews typically lasting from 1-3 hours). Unfortunately we delegated the responsibility to find interesting material to assistants who, in retrospect, were insufficiently prepared for this task.

Despite our lack of success, we continue to believe that qualitative data can be obtained as a bonus in connection with quantitative data collection from key informants. To improve chances of success, however, notes need to be made soon after each interview as to whether or not the interview contains useful qualitative information, the locations in the interview where such comments are made, and a brief description of the topics covered by the comments. It might then be possible to assign the transcription to assistants if they are sufficiently trained and monitored.

*6) A multi-method strategy towards research on AIDS parents using innovative techniques to data collection can help overcome the shortcomings of any particular specific approach.*

Given all the problems faced by research into the situation of AIDS parents, there is unlikely to be any single ideal data collection strategy. As noted, for a variety of reasons, it is very difficult to obtain information for or from a probability sample of AIDS parents. Thus innovative alternative strategies for data collection must be employed. In our project we used five different strategies to collect information on the impact of the AIDS epidemic on the older aged parents of those who succumb to the disease. None involved probability samples and, as shown above, some clearly differ in basic characteristics from the populations they are intended to represent. More generally, each individual approach had weaknesses. Yet in important respects the information they provided complemented each other and provided a basis for assessing and taking their relative biases into account when interpreting results. The full value of a multi-method approach, however, can only be realized by integrating analysis based on the different methods, something which is often done only to a very limited extent (Booyesen and Arntz 2003).

Employing a variety of data collection strategies to obtain information from a variety of perspectives can also provide an important check for findings that are surprising or controversial. For example, we found much less stigma towards families affected by AIDS than is generally reported by the popular media, by organizations that seek to help PLWHA and their families, and by researchers using small or non-systematic samples (VanLandingham, Im-em and Saengtienchai 2002). Where such a controversial finding is robust to varying methods and approaches (as it is in this case), it will increase confidence in the validity of the finding. Conversely, such a range of approaches will also protect against being misled by an influential but misinformed (single) source. One high-level provincial health official we interviewed was quite confident that most people in the province did not accept PLWHA, a point of view that was contradicted by the extensive community based data that we subsequently collected there.

Qualitative analysis can usefully complement but not substitute for more systematic quantitative data collection if we wish both to gain some in-depth understanding of the experiences of AIDS parents and have a reasonable sense of the frequencies of particular situations. Both open-ended and survey interviews, however, are likely to share some of the same selection biases that a survey of AIDS parents suffers. In particular, parents whose relationship with their adult child had been strained, who avoided or minimized involvement with their ill child, or whose experiences were particularly painful, will likely be less willing to grant either type of interview.

It is essential to be constantly vigilant of the selectivities involved in different data collection approaches, especially when standard probability sampling is not a viable option. This is a problem that characterizes impact studies generally and not just those focusing on AIDS parents (Booyesen and Arntz 2003). One important consideration is the time frame to which the collected information refers. Data which refer to situations before the terminal stage of illness and death of an adult child, such as provided by PLWHA group members, can seriously underestimate the eventual involvement of AIDS parents in caregiving and support. On the other hand, data from parents whose child already died of AIDS but who are identified by local intermediaries for a direct interview survey will likely overstate parental involvement because of insufficient knowledge on the part of intermediaries of parents whose child remained away from the locality where the parents lived during the entire period of illness. Fortunately, since many of these biases become evident once results from the different components are compared, they can be factored into the interpretation of findings.

## **VI. Conclusion**

Since most adults with AIDS have at least one and often two living parents, worldwide there are millions of older persons who have already lost an adult son or daughter to the disease, and many millions more who will in the near future. Yet very little systematic research has explored the types of difficulties that befall them as a result of this tragedy, or the short-term and long-term consequences of these difficulties. Thus even if in practice the methodological compromises that are required to carry out such research preclude precise quantitative estimates of the situation, providing reasonable approximations along with an informed sense of the direction and extent of bias involved are important steps forward. Being able to distinguish, for example, between specific impacts on AIDS parents that are fairly common and those that occur infrequently, can also be very helpful in guiding the design of programs intended to ameliorate the adverse consequences resulting from the illness and loss of an adult child.

Efforts to collect data that can adequately document with reasonable accuracy how older persons are affected as parents of those who become ill with and die of AIDS present a variety of challenges. Many of these challenges, including the difficulty of obtaining representative samples, are shared by research on the impact of the epidemic generally (Booyesen and Arntz 2003). These difficulties, however, should not discourage efforts to pursue such research given the immense importance of the subject matter. Our experience in conducting such research in Thailand indicates that, with innovative approaches tailored to the problem and the particular setting, a wide variety of data of reasonable quality can be generated that can help target resources for this substantial and widely-affected population.

Table 1. Approaches used in Thailand project to data collection on the situation of AIDS parents - summary of main features

	Key informant interviews	Open-ended interviews	Direct interview survey	Assisted self-administered questionnaires	Welfare applications
Type of data generated	quantitative (and limited qualitative)	qualitative	quantitative	quantitative	quantitative
Person providing the information	local health staff, health volunteer, or other local informant	AIDS parent	AIDS parent or comparable group of non-AIDS parent	Member of support groups for persons living with HIV/AIDS	Applicant for welfare designated for persons ill with AIDS or their families
Method of data collection	Interviews by PIs with informants using structured, largely pre-coded, forms to record information	Tape recorded open-ended interviews by PIs using guidelines for topics to be covered	Structured close-ended questionnaires administered by interviewers supervised by PI	Self administered questionnaires usually with guidance available from a project representative	Extraction of information in application onto pre-coded forms by PIs and assistants
Number and nature of cases	Basic data for 195 adults currently ill with AIDS and 768 who died of AIDS during prior few years in locality; more detailed data for a subset of 285	Verbatim transcripts in Thai and English of 18 interviews with parents who cared for an adult child who died of AIDS (and two with other types of family caregivers).	394 detailed interviews with parents of adults who died of AIDS during prior few years and 376 interviews with non-AIDS parents	408 active HIV+ members of PLWHA groups	826 adults who were ill with AIDS at the time of application (covered prior few years)
Area from which sample was drawn	85 local sites in 8 provinces from all 4 regions and Bangkok	Bangkok and 3 provinces in two regions	3 provinces from different sub-regions	Bangkok and 3 provinces from 2 regions	6 provinces from all 4 regions
Year data were collected	1998-99 (most in 1999)	1998-99	2000	1999-2000	1999

Note: PI = Principal investigator

Table 2. Comparison of age, sex and marital status among nationally recorded adult HIV+ cases and samples from key informants, PLWHA group members, and welfare applicants

Percentage distribution by	Nationally recorded AIDS cases 1997/1999	Cases reported by key informants (currently symptomatic or deceased)	Deceased children as reported by AIDS parents in direct interview survey	PLWHA group members	Welfare applicants
Sex					
Male	75.3	73.9	79.8	33.5	53.0
Female	24.7	26.1	20.2	66.5	47.0
Total	100	100	100	100	100
Age					
20-24	10.8	11.4	9.6	9.9	13.6
25-29	29.5	30.1	33.2	30.8	29.7
30-34	26.9	24.7	33.4	28.1	29.9
35-39	15.8	17.1	15.5	16.0	15.5
40+	16.9	16.8	8.3	15.3	11.4
Total	100	100	100	100	100
Marital status(a)					
Single	33.0	29.9	29.4	12.6	23.0
Married	58.2	49.2	45.7	27.2	39.1
Divorced/ separated	4.3	9.1	12.9	13.3	8.5
Widowed	4.5	11.8	11.9	46.3	28.9
Total	100	100	100	100	100
N of cases (b)	--	960	394	406	826

Note: a) the marital status distribution for the nationally recorded HIV+ cases refer to 1997/1998 and are from special tabulations provided on request to the Ministry of Public Health. The marital status distributions from this source and from the survey of AIDS parents include ages 15-19.

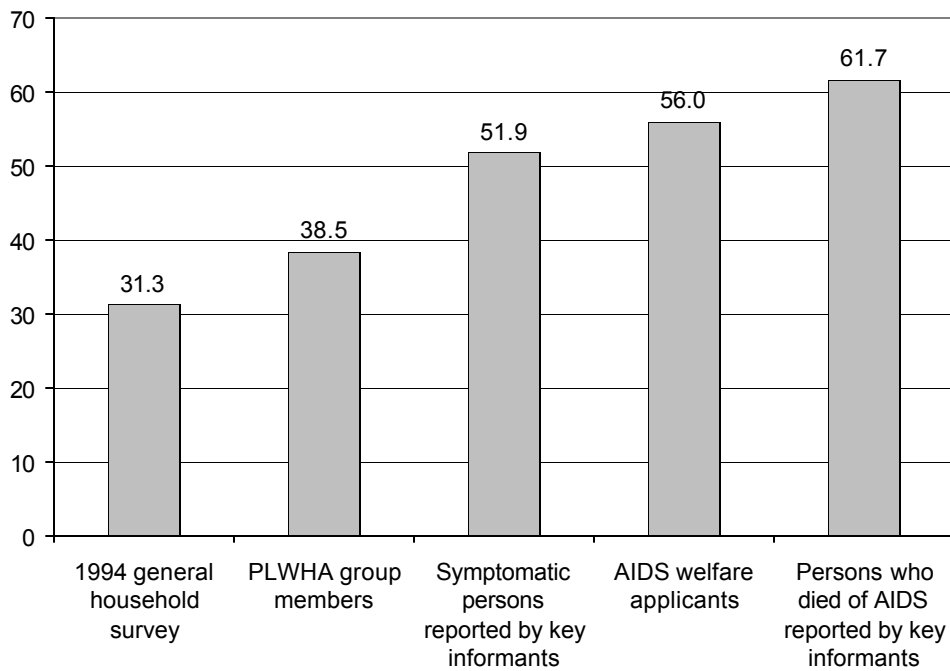
b) Includes cases with missing values on some variables.

Table 3. Measures of parental caregiving according to data source, Thailand

Reference population and data collection approach	Percent of cases for whom a parent gave care	Percent of cases for whom a parent was a main caregiver
All adult HIV/AIDS cases		
Key informant study		
Currently symptomatic cases	34.8	26.7
Deceased cases	64.5	49.7
PLWHA member survey	42.5	22.2
Adult HIV/AIDS cases with a living parent		
Key informant study*		
Currently symptomatic cases	42.1	32.4
Deceased cases	76.9	59.3
Direct interview survey with AIDS parents	91.1	71.3
PLWHA member survey	47.6	27.6

\*Adjusted for the 8 percent of cases for whom key informant did not know the living status of the parents assuming that the proportion with a living parent is two-thirds that of the equivalent 5-year age group based on cases for whom the parents' living status is known. Given the small percentage of cases involved, results are only minimally affected by this assumption.

**Figure 1. Percent living with a parent according to data source, Thailand**



## Reference List

- Aggleton, Peter and Ian G. U. Warwick. 1999. *Community Responses to AIDS, Part 2 in UNAIDS, Sex and Youth: Contextual Factors Affecting Risk for HIV/AIDS: A Comparative Study of Multi-Site Studies in Developing Countries*. Geneva: UNAIDS.
- Ainsworth, Martha and Julia Dayton. 2001. *The Impact of the AIDS Epidemic on the Health of the Elderly in Tanzania*.
- Barnett, Tony. 2002. "HIV/AIDS Impact Studies II: Some Progress Evident." *Progress and Development Studies* 23:219-25.
- Barnett, Tony and Alan Whiteside. 2000. *Guidelines for Studies of the Social and Economic Impact of HIV/AIDS*. Geneva, Switzerland: UNAIDS, Best Practice Collection.
- Barnett, Tony, Alan Whiteside, and Chris Desmond. 2001. "The Social and Economic Impact of HIV/AIDS in Poor Countries: a Review of Studies and Lessons." *Progress and Development Studies* 1(2):151-70.
- Brabant, S. 1994. "An Overlooked AIDS Affected Population - the Elderly Parent As Caregiver." *Journal of Gerontological Social Work* 22(1-2):131-45.
- Booyesen, F. and Tanja Arntz. 2003. "The Methodology of HIV/AIDS Impact Studies: a Review of Current Practices." *Social Science & Medicine* 56 :2391-405
- Bryant, John and Aree Prohmmo . 2002. "Equal Contribution and Unequal Risk in a North-East Thai Village Funeral Society ." *The Journal of Development Studies* 38 (3):63-75.
- Dane, Barbara O. 1991. "Anticipatory Mourning of Middle-Aged Parents of Adult Children With AIDS." *Families in Society-the Journal of Contemporary Human Services* 72(2):108-15.
- Danziger, Renee. 1994. "The Social Impact of HIV/AIDS in Developing-Countries." *Social Science & Medicine* 39(7):905-17.
- Dayton, Julia and Martha Ainsworth. 2002. *The Elderly and AIDS: Coping Strategies and Health Consequences in Rural Tanzania. Policy Research Division Working Paper No. 160*. New York: Population Council.
- DeVries, Brian, Rose D. Lana, and Vilma T. Falck. 1994. "Parental Bereavement Over the Life-Course - a Theoretical Intersection and Empirical Review." *Omega-Journal of Death and Dying* 29(1):47-69.
- Ellis, M. and C. Muschkin. 1996. "Migration of Persons With AIDS - a Search for Support From Elderly Parents?" *Social Science & Medicine* 43(7):1109-18.
- Gregory, D. and A. Longman. 1992. "Mothers' Suffering: Sons Who Died of AIDS." *Qualitative Health Research* 2(3):334-57.
- Gurmessa, Muluaem. 1999. "The Social Effects of AIDS on the Elderly." Senior essay, Department of Sociology and Social Administration, College of Social Sciences, Addis Ababa University, Addis Ababa, Ethiopia.
- Im-em, Wassana, Mark VanLandingham, John Knodel, and Chanpen Saengtienchai. 2001. *Knowledge and Attitudes of Older People About HIV/AIDS in Thailand: A Comparison With Young Adults*. Publication No. 257, Institute for Population and Social Research, Mahidol University, Thailand.
- Knodel, John. 1993. "The Design and Analysis of Focus Group Studies in Social Science Research." Pp. 35-50 in *Successful Focus Groups: Advancing the State of the Art*, David Morgan. Newbury Park, CA: Sage.
- Knodel, John, Wassana Im-em, Chanpen Saengtienchai, Mark VanLandingham, and Jiraporn Kespichayawattana. 2002. *The Impact of an Adult Child's Death Due to AIDS on Older-Aged Parents: Results From a Direct Interview Survey*. 266. Bangkok: Mahidol University, Institute for Population and Social Research.
- Knodel, John and Chanpen Saengtienchai. 2002. *AIDS and Older Persons: The View From Thailand*. Research Report 02-497. Ann Arbor, MI: Population Studies Center, University of Michigan.
- Knodel, John, Chanpen Saengtienchai, Wassana Im-em, and Mark VanLandingham. 2000. *The Impact of Thailand's AIDS Epidemic on Older Persons: Quantitative Evidence From a Survey of Key Informants*. IPSR Publication No. 252. Bangkok: Mahidol University, Institute for Population and Social Research.
- Knodel, John and M. VanLandingham. 2002. "The Impact of the AIDS Epidemic on Older Persons. " *AIDS* 2002 16 (suppl. 4):S77-S83.

- Knodel, John and Mark VanLandingham. 2003. *Social Science & Medicine* 57(2):27-342.
- Knodel, John, Susan Watkins and Mark VanLandingham. 2003. "AIDS and Older Persons: An International Perspective." *Journal of Acquired Immunodeficiency* (forthcoming).
- Kongsin, Sukhontha, Sukhum Jiamton, Charlotte Watts, and Angsana Boonthum. 2001. "Conducting a Household Survey on the Economic Impact of Chronic HIV/AIDS Morbidity in Rural Thailand: Methodological Issues ." *Journal of Health Science* 10(2):236-45.
- Longman, A. J. 1995. "Connecting and Disconnecting: Bereavement Experiences of Six Mothers Whose Sons Died of AIDS." *Health Care for Women International* 16(1):85-95.
- Moss, M. S., E. L. Leshner, and S. Z. Moss. 1986. "Impact of the Death of an Adult Child on Elderly Parents - Some Observations." *Omega-Journal of Death and Dying* 17(3):209-18.
- Muecke, Majorie. 2001. "Women's Work: Volunteer AIDS Caregiving in Northern Thailand *Women and Health*, 33(1/2), 21-37." *Women and Health* 33(1/2):21-37.
- Paul, Godfred. 2001. *When the Boomerang Returns: a Qualitative Study of the Socioeconomic Impact of HIV/AIDS on Older People in Northern Thailand* . unpublished manuscript.
- Peabody, B. 1986. "Living With AIDS - a Mothers Perspective." *American Journal of Nursing* 86(1):45-46.
- Saengtienchai, Chanpen and John Knodel. 2001. *Parents Providing Care to Adult Sons and Daughters With HIV/AIDS in Thailand*. Geneva: UNAIDS.
- Sanders, C. M. 1980. "A Comparison of Adult Bereavement in the Death of a Spouse, Child, and Parent." *Omega-Journal of Death and Dying* 10(4):303-22.
- Seidel, John. 1998. *Ethnograph V5.0: A Users Guide*. Thousand Oaks, CA: Scholari.
- Urassa, Mark, J. T. Boerma , Raphael Isingo, Juliana Ngalula, Japheth Ng'eshemi, Gabriel Mwaluko, and Basia Zaba. 2001. "The Impact of HIV/AIDS on Mortality and Household Mobility in Rural Tanzania." " *AIDS* 15:1-7.
- USAID, UNAIDS, and UNICEF. 2002. *Children on the Brink, 2002:A Joint Report on Orphan Estimates and Program Strategies*.
- VanLandingham, Mark and Wassana Im-em. 2001. *Living With HIV/AIDS in Thailand: Results From a Self-Administered Survey*. University of Michigan Population Studies Center Research Report No. 01-488.
- VanLandingham, Mark, John Knodel, Wassana Im-Em, and Chanpen Saengtienchai. 2000. "The Impacts of HIV/AIDS on Older Populations in Developing Countries - Some Observations Based on the Thai Case." *Journal of Family Issues* 21(6):777-805.
- VanLandingham Mark, Wassana Im-em, and Chanpen Saengtienchai. 2002. *Community Reaction to Persons With HIV/AIDS and Their Parents in Thailand*. University of Michigan Population Studies Center Research Report No. 02-530.
- Williams, Alun and Grace Tumwekwase. 2001. "Multiple Impacts of the HIV/AIDS Epidemic on the Aged in Rural Uganda." *Journal of Cross-Cultural Gerontology* 16:221-36.
- World Health Organization. 2002. *Impact of AIDS on Older People in Africa: Zimbabwe Case Study*. WHO/NMH/NPH/ALC/01.12. Geneva: WHO.