

Researching the Impact of the AIDS Epidemic on Older-age Parents in Africa: Lessons from Studies in Thailand

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Introduction

Both Africa and Asia are facing the effects of the HIV/AIDS pandemic. The chief focus in debates on the epidemic continues to be on the prime-age adults who are mainly affected and killed by the disease, and on the AIDS orphans left by them. However, recent years have seen an emerging international recognition, in particular at UN-level, of the critical importance of considering older people in identifying the impacts and possible responses to the epidemic (UN, 2002).

Large numbers of older people, in particular, the parents of AIDS victims, are directly affected by AIDS. On the one hand, such parents, who are typically in their 50s, 60s and 70s, suffer the adverse consequences of losing a child (Knodel, Watkins and VanLandingham 2002). On the other hand, they play a critical part in helping families and societies to cope with the disease – in particular through their role as carers for their adult children dying from the disease, and guardians for their grandchildren orphaned by it.

Overall efforts to address the impacts of the pandemic in Africa as in Asia, therefore, must crucially identify ways in which older people, in particular AIDS parents, can be supported. A prerequisite for this is a meaningful understanding of the nature and determinants of the impacts that HIV/AIDS has on older adults, as well as solid evidence on the scope and extent of these impacts in the population.

In Africa, such an understanding and evidence is largely absent to date, largely owing to the dearth of comprehensive research needed to generate it. In Asia, in contrast, in-depth and wide-ranging research on the situation of older people affected by AIDS has emerged in recent years, in particular in Thailand¹. The experience from this research has generated numerous insights and potentially valuable lessons, which can be drawn on in the design of African research in this area. Such 'South-South' exchange is an important, though to date not fully developed, part, of the overall endeavour to advance research on ageing in Africa as in other developing regions.

The main aim of this paper, therefore, is to describe the methodological challenges faced and insights gained in the Thai research² and, in light of these, to distil the lessons learnt that might be valuable for

African researchers developing research on AIDS and older people.

The current field of research on AIDS and older people

To bring into relief the insights gained and lessons learnt from the Thai research, it is useful, first, to sketch the range of approaches and orientations that are currently brought to bear on research on AIDS and older people.

Two broad research orientations currently dominate the field. First, participatory research (Cornwall and Jewkes, 1995), which is often conducted by NGOs and geared toward advocacy or programme development, and which is typically characterized by relatively narrowly framed questions and samples. In Africa there is a growing body of such research, with two prime examples being a recent study conducted by HelpAge International in Tanzania (HAI, 2004) and a WHO study in Zimbabwe (WHO, 2002; HAI, 2004).

The second dominant strand is the more 'conventional' academic research, which can employ a range of methods and levels of analysis and aims more broadly to gather basic information on the situation of older people living with or affected by AIDS. Examples of such research in Africa include ethnographic-style research (Williams and Tumwekwase, 2001; Williams, 2003), general qualitative investigations (Tlou, 1996; Ingstad, Bruun, and Tlou, 1997; Gurmessa, 1999; Appleton, 2000; Ssengonzi, under review;), mixed method studies typically combining in-depth interviews with small-scale surveys (Baylies, 2002; Nyambedha, Wandibba, and Aagaard-Hansen, 2003), and predominantly quantitative studies, which use single-round small-scale surveys (Kakooza, 2004) or panel surveys (Ainsworth and Dayton, 2003; Dayton and Ainsworth, 2004; Hosegood and Timæus, 2004) and employ a range of simple and advanced statistical techniques. Finally, some studies have employed complex simulation and projections (Clark, 2004; Merli and Palloni, 2004)³.

The Thai research we report on here falls into this latter category and it employed a systematic analysis of empirical evidence derived mainly through original data collection.

A framework for assessing the situation of AIDS parents

Research that can adequately assess the situation of AIDS parents, needs to follow a framework that

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enables examination of the full range of potential impacts they may encounter and the pathways through which they come about (VanLandingham, Knodel, Imem, and Saengtienchai, 2000; Knodel *et al.* forthcoming). These impacts are likely to be multi-dimensional and affect the emotional, economic, social, and physical wellbeing of the parents. Emotional distress over the adult child's suffering during illness and grief following the child's death are likely universal. Parents may experience economic strain emerging from a son or daughter's illness, especially if the parents help with medical costs and living expenses, curtail their economic activity to give care, pay funeral costs, or take responsibility for orphaned grandchildren. The loss of current or future support from the child can leave the parents in financial difficulty. The health of older-aged parents could suffer through physical strains associated with caregiving, extra work taken on to pay expenses, or potential exposure to TB or other opportunistic diseases that persons with AIDS often suffer. Stigma may lead parents to withdraw from normal community life or cause others to sever contact with them.

Determining the actual nature and extent of these impacts requires systematic and appropriate empirical investigations, which take into account the particular cultural, political and socio-economic and health sector setting in which the HIV/AIDS epidemic unfolds, as well as the severity of the epidemic (Knodel, Watkins, and VanLandingham, 2003).

The Thai setting in which our project was conducted is characterised by features which, on the one hand, markedly differ from the context in most African nations, namely the only moderate adult HIV prevalence, a well-developed public health and health insurance system, widespread availability of government health insurance, and successful AIDS awareness and education efforts. Other features, on the other hand, are likely similar to those of African setting, including the predominance of heterosexual transmission of HIV, social tolerance of transactional sex, a lack of extensive formal support and services for persons with AIDS, high levels of past fertility for the older generation, and the dependence of parents on adult children for old-age support often involving co-residence. Together, these features influenced the research design, the challenges faced and the solutions found, and they need to be borne in mind when drawing lessons for research in Africa or elsewhere.

Methodological challenges and Thai solutions

The research, broadly, employed a multi-method approach. Quantitative data were mainly generated using 1) interviews with key informants yielding information for close to 1000 individual AIDS cases and their families and 2) a direct survey consisting of almost 800 interviews divided equally between AIDS and non-AIDS parents. Qualitative data were generated from a series of 18 open-ended interviews with AIDS parents (see Table 1). Supplementary quantitative information was collected through assisted self-administered questionnaires from persons living with HIV/AIDS and through extraction of information from application forms for welfare assistance related to AIDS⁴.

The design and conduct of the study met with three

Table 1. Approaches Used in Thailand Project to Data Collection on the Situation of AIDS Parents – Summary of main features

	Case information from key informant interviews	Open-ended interviews	Direct interview survey
Type of data generated	quantitative (and limited qualitative)	qualitative	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
Method of data collection	interviews by principal investigators with informants using structured, largely pre-coded, forms to record information	tape recorded open-ended interviews by principal investigators using guidelines for topics to be covered	structured closed-ended questionnaires administered by interviewers supervised by principal investigators
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
Area from which sample was drawn	85 local sites from all 4 major regions and capital city	capital city and 3 provinces in two regions	3 provinces from different sub-regions

major methodological challenges, namely (i) the extended time frame in which impacts may occur, (ii) the sensitivity of the topic, and (iii) identifying and obtaining information for an appropriate sample. These challenges, which will likely also face research on this issue in Africa, are reflected on in some detail below.

Time frame

One important issue that needed a decision at the start, and that will arise in any research on AIDS parents, concerned the time frame we should consider for impacts. Most impacts occur only after the child becomes seriously ill. Some are immediate and short-term, occurring either during the period of illness when the parent might be involved in caregiving or shortly after the death when the funeral takes place and mourning is particularly intense. Others can be prolonged such as fostering orphaned grandchildren. Still others could be substantially delayed and manifest themselves only after the parents are frail or economically inactive and need to depend on adult children for care and support. Assessing these longer-term impacts would require either a longitudinal design, with the inconvenience of a very lengthy research period, or retrospective reporting of information about events far in the past, risking serious recall error and bias. Our decision was to focus mainly on situations in which the adult child with AIDS had already died but within a period between 6 months and three years prior to data collection. This compromise allowed some time for

post-death impacts to emerge but was recent enough to reduce serious recall error.

The time frame chosen for a research project has important implications for the findings. Both our Thai research and studies in Africa make clear that living and caregiving arrangements of persons with HIV/AIDS often change during the course of their illness (Williams and Tumwekwase, 2001; World Health Organization, 2002; (Knodel and VanLandingham 2003). HIV infected adult children who live elsewhere often return to their parents at advanced stages of illness, when they can no longer support or care for themselves. Sometimes parents move temporarily to join their seriously ill child to provide care. Even HIV infected sons or daughters who reside near or with parents from the onset of illness may need parental caregiving only at the terminal stage, after self care is no longer possible or their spouse leaves. Thus only caregiving histories of adult children who already died will reveal the full extent of parental involvement. Studies of caregiving that focus on persons who are currently living with HIV/AIDS are likely to underestimate seriously the involvement of parents.

The time frame chosen for the research will also influence the extent that AIDS parents are found to foster orphaned grandchildren. In our Thai research, a large share of the young children who had lost only one parent at the time of our research were being cared for by the surviving parent. Since some of these parents are also HIV infected, they are likely to die before their children grow up, at which point the orphan may go to a grandparent. This is strongly suggested by our finding that most orphans who lost both parents are cared for by grandparents, in contrast to those with a surviving parent (Knodel *et al.*, 2001). Thus the full extent of grandparent fostering only evolves over time and shorter time frames will underestimate this impact.

Sensitivity of the subject matter

One source of difficulty we anticipated at the start of our Thai research was the social and emotional sensitivity of the subject matter. We assumed that talking about the loss of an adult child would be emotionally difficult for a parent, especially when the loss was due to AIDS. Thus we did not initially try to conduct a face-to-face survey of substantial numbers of AIDS parents using a closed-end questionnaire intended for quantitative analysis, but rather interviewed only a small number using an open-ended interview approach to obtain data for qualitative analysis. To gain sufficient data for quantitative analysis, we decided instead to interview key informants who could provide information (on an anonymous basis) for a substantial number of individual cases. This avoided problems that might arise from an unwillingness of AIDS parents to be interviewed.

The open-ended interviews were arranged by intermediaries in the community where they took place. This ensured a willingness to be interviewed on the part of those parents who agreed before we contacted them ourselves. Our interview guidelines purposively avoided reference to AIDS as the cause of death (note we already knew this from the intermediary). In fact, most interviewees mentioned AIDS themselves and talked openly about it. We also assured the interviewees that information they provided was confidential and that no names would be attached to the data we

collected, although few seemed concerned about this matter. We also found that most of the parents we spoke with welcomed an opportunity to share their grief with someone willing to listen, even if it sometimes evoked strong emotional reactions.

The experience with the open-ended interviews as well as discussions with our key informants led us to reconsider conducting a face-to-face survey of AIDS parents using a questionnaire and later in the project we carried such a survey out (including a sample of non-AIDS parents). As with the open-ended interviews, we relied on intermediaries to arrange for interviews once we picked a sample (see below), we made no explicit reference to AIDS in the questionnaire, and we assured respondents of the anonymity and confidentiality of the results.

Identifying and obtaining information from an appropriate sample

A particularly critical challenge we faced was to identify an appropriate sample of sufficient size to make quantitative assessments. Given the lack of any standard sampling frame, we realized that whatever method we chose was virtually certain to involve selection biases. Thus we wanted not only to minimize such biases but also to understand how they came about so we could take them into account when interpreting our results. One practical solution for us was to sample study sites and then to rely on knowledgeable local persons to serve as key informants who could both identify cases and provide information about them that could serve as data for quantitative analysis. In rural areas, we relied primarily on local government health station staff. In the urban sites informants were more varied and included neighbourhood health volunteers and local community leaders. Basic information on living arrangements and caregiving was obtained in this way for sizeable numbers of adults who died of AIDS as well as some who were currently symptomatic. In addition, more detailed supplemental information was asked about the subset of cases that the informants knew best. We also relied on local health personnel when conducting the survey of AIDS and non-AIDS parents to identify and list potential respondents. For the AIDS parents sample, we only interviewed parents whose child already died. In the remainder of this section only the AIDS parents part is discussed.

The two approaches have different strengths and weaknesses and complement each other. The AIDS parents survey, which interviewed the parents themselves, has the obvious advantage that parents know far more about their own situation than would any key informant. However, the sample of parents interviewed is biased towards parents who were involved in caregiving. This arises mainly because local health staff could far more readily identify local parents whose child died in the community than those whose child died elsewhere. Since parents whose child died locally will be more likely to be involved in caregiving than parents whose child remained away, parental caregivers are overrepresented in the survey. In addition, this bias would be compounded if parents who provided less assistance to their ill adult child were less willing to be interviewed. Nevertheless the AIDS parents survey data should at least reasonably represent parents who were involved in caregiving even if not the full range of AIDS parents.

The case data provided by key informants is limited to even more basic information. However these data are more broadly representative than the AIDS parents survey. It was relatively easy for informants to identify all cases who died of AIDS locally regardless of where the parents lived. Although informants often knew little about parents who lived elsewhere, if the child remained in the locality until death and the parents did not come to help, we can assume at least that the parents were not involved in caregiving. In addition, information obtained from key informants did not depend on the willingness of the parent to be interviewed.

Figure 1 illustrates several of the methodological points discussed above by comparing results from the two sources. Each bar represents the percent of cases for whom a parent was reported to be a main caregiver. The lowest estimate refers to case information from key informant interviews on adults who were still alive and currently symptomatic. The middle estimate is based on key informant reports about cases who already died of AIDS. The much higher percent of parental caregiving for adult children who already died reflects the fact that parental caregiving often starts only at the terminal stage of illness. The highest estimate is from the AIDS parents survey and is surely an overestimate reflecting the selection bias in the direct interview survey towards parents who provided care.

Theoretically, a general household survey based on a probability sample to identify AIDS parents for interviews would yield appropriate proportions of both parents whose child died locally and those whose child died elsewhere. We judged such an approach to be impractical in Thailand where the modest HIV prevalence would require a very large sample to locate sufficient cases of AIDS parents. Even in high prevalence contexts such an approach could be problematic. To yield representative information, AIDS parents contacted must be willing to be interviewed, to admit that an adult child died, and to provide sufficient information to determine if AIDS was the cause of death. If differences in willingness to be interviewed and provide the required information are related to the outcome variables of interest, the survey would also produce biased results. Note when using intermediaries to identify AIDS parents, as we did, there is no need to determine cause of death from the respondents themselves. Of course either approach risks misidentification.

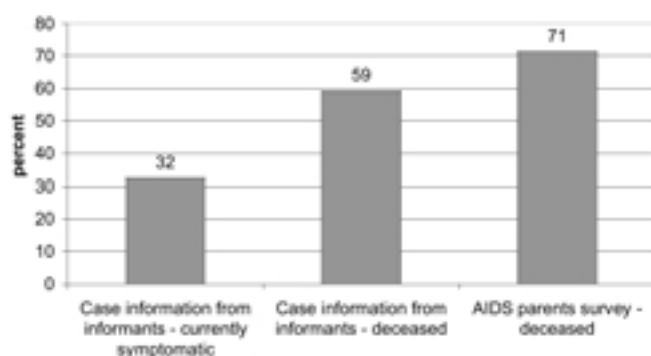


Figure 1. Percent of cases for whom a parent was a main caregiver, among adults with AIDS who have at least one living parent, by source of information

Some general lessons learned

While there is much that distinguishes Thailand from Africa and other settings, some of the methodological challenges discussed above will arise in other locales as well. Thus it is worth considering lessons from our experience that could have relevance for research elsewhere.

1) *The research plan is best developed in successive steps with allowance for modifications as the project progresses.*

The paucity of prior research on AIDS parents means that there are few precedents to guide a research design. The full range of potential data sources, how to best take advantage of them, and how usefully to combine them is likely to be unknown. In our Thai research, an initial two-week pilot project that enabled us to assess the situation as it actually existed in the field was critical for our efforts to develop a realistic research plan. In addition, we needed to substantially modify our plan during implementation as we continued to learn more about the potential sources and their limitations. As noted, although we were initially reluctant to conduct a direct interview survey with AIDS parents, our views as to its feasibility changed as we gained more experience in the field. Given that the research will be charting new territory in most cases, a step-by-step approach that allows for modification of the design can be advantageous.

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

The necessity for innovative data collection approaches combined with the complexity of research that incorporates multiple methods means that principal researchers need to be actively involved throughout the data collection process. Only the principal researchers will have sufficient understanding of the research goals and the substantive issues underlying them to develop the study design in the stepwise approach advocated above. They thus need to be present during early contacts in the field in order to ensure that their final designs are suitably adapted to the actual situation. Developing and pretesting newly developed methods and instruments likewise require direct involvement of the key investigators. For example, developing a questionnaire for a survey of AIDS parents or interview guidelines for more open-ended discussions can require a great deal of pretesting and re-assessing given the sensitive and multi-faceted issues of interest. Moreover during actual fieldwork involving an innovative approach, unanticipated problems are likely to arise that require many on-the-spot decisions. Delegating responsibility for this can be risky.

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

Key informants are typically associated with ethnographic and other 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 strategy. Although key informants can provide only rudimentary information, the strategy has several major advantages. First, it can identify substantial numbers of cases in the absence of registers or other suitable

sources. Second, it avoids problems associated with the sensitivity of the topic since those to whom the information refers are not directly involved. Third, it is efficient because one key informant interview can provide data for multiple cases. For this approach to work, however, researchers need to access informants who are familiar with most or with at least a representative range of AIDS cases in their locality and who are willing to provide the information requested. A key informant approach also carries potential risks. Any particular informant might have selective familiarity with cases in ways that could bias results. Thus, if possible, it is useful to have several informants join the interview to improve the completeness of the cases identified and the information provided.

4) *Intermediaries can greatly facilitate the identification and recruitment of survey respondents.*

While a general household probability sample to find and interview AIDS parents is unlikely to be feasible in most settings, a practical alternative strategy is to enlist local health staff to act as intermediaries to identify AIDS parents and obtain their agreement to be interviewed 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. The success of this strategy requires enlisting intermediaries who are in a position to know which parents lost an adult child to AIDS, to have a means to contact these parents, and to have their trust and respect to solicit their willingness to be interviewed. One weakness of this strategy is the difficulty intermediaries may have in identifying parents whose adult child died of AIDS elsewhere thus biasing the sample towards parents whose child died locally.

5) *Allow for a full range of outcomes when framing research questions, developing instruments and conducting analyses*

When preparing and carrying out basic academic research on AIDS and older persons, it is useful to review previous related research regardless of the approach used as well as the advocacy literature from NGOs and popular treatments in the media. At the same time, it is essential not to allow preconceptions derived from this review skew the range of outcomes allowed for when formulating the research questions, developing the data collection instruments and analyzing results. This can be a particular risk when most of the received wisdom is based mainly on anecdotal data and advocacy research. Anecdotal data usually emphasizes extreme cases while research for advocacy purpose is often quite selective in the questions asked and in the cases included for study. Impressions gained from such information may end up being correct but just as possibly can be misleading by oversimplifying a far more nuanced situation or emphasizing only one side of the picture.

Our Thai research on community reaction to AIDS provides a cautionary example. As elsewhere, the discourse about the AIDS epidemic in Thailand portrays the disease as stigmatized and emphasizes examples of negative community reaction to persons with AIDS and their families, based mainly on anecdotal data or small or non-systematic samples. Yet the extent of stigma is likely to vary considerably over time and across settings. Thus when developing a ques-

tionnaire or interview guidelines that deals with community reaction, it is important to ask not just about negative reactions but also positive ones. Our research did find evidence of negative community reaction but far more common were reports of supportive reactions. In addition, negative reactions declined substantially over time (VanLandingham, Im-em, and Saengtienchai, 2002). Interestingly, some similar findings are beginning to emerge for Africa (Muyinda *et al.*, 1997; Chimwaza and Watkins, 2004).

Gender issues is another area where preconceived notions can prevent a fuller picture to emerge. Most discussions about AIDS caregiving in the developing world emphasize the role of women. Women undoubtedly provide more personal care to persons with AIDS than do men. Yet men may contribute in ways that are more indirect or less obvious. For example, many studies fail to consider instrumental aspects of care (such as providing transportation) that men often provide. To more adequately assess gender roles in caregiving, data collection instruments need to inquire not just about tasks that typify women but also include items that can draw out men's contribution.

6) *Open-ended interviews can provide rich insights that compliment quantitative findings*

Qualitative analysis of open-ended interviews with AIDS parents can facilitate the understanding of situations that are complicated or that for other reasons are not readily captured in closed-ended questionnaires commonly used to collect data for quantitative analysis. Results can also help when designing instruments intended for quantitative data collection. The conversational style allows and encourages interviewees to elaborate their views and readily permits probes for clarification. It is also suited for building rapport, a particularly important feature when discussing matters as sensitive as losing an adult child to AIDS. Because qualitative analysis is time-intensive, the number of open-ended interviews will typically be small and thus results can serve only an illustrative role. Yet our experience clearly confirms the view of others that a qualitative component in AIDS impact studies is a useful complement to broader based quantitative data collection ((Booyesen and Arntz 2003)).

7) *A multi-method strategy, especially when using innovative data collection techniques, helps overcome shortcomings of any single approach.*

Given the many problems faced by research into the situation of AIDS parents, there is no single ideal data collection strategy, particularly given the difficulty in obtaining information based on a broad based probability sample. Thus innovative alternative strategies are likely to be required each of which will have weaknesses and frequently involves selection biases, a problem that characterizes impact studies generally ((Booyesen and Arntz 2003)). Yet information provided by carefully designed alternative strategies can complement each other. By integrating analysis based on the different methods and by taking their relative biases into account when interpreting findings, a reasonable set of results can be achieved.

Employing a variety of data collection strategies can also provide an important check for findings that are surprising or controversial. As noted above, our research found much less stigma towards families affected by AIDS than is generally reported elsewhere

by others (VanLandingham, Im-em, and Saengtienchai, 2002). Where such a controversial finding is robust to varying methods and approaches (as it is in this case), its credibility is greatly enhanced. Conversely, a range of approaches will also protect against being misled by peculiar results from a single source.

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 little systematic research has explored the difficulties that befall them, or their short-term and long-term consequences. Thus even if in practice 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 extent of bias involved are important steps forward. Being able just to distinguish, for example, between

specific impacts on AIDS parents that are fairly common and those that occur infrequently, can still be very useful for guiding the design of programs to address the adverse consequences.

The collection of data that can adequately document with reasonable accuracy how older persons are affected as parents of afflicted adults who die of AIDS presents many challenges. This should not, however, discourage efforts to pursue such research given the immense importance of the subject matter. Our experience in Thailand indicates that, with innovative approaches tailored to the problem and setting, a wide variety of data of reasonable quality can be generated and much can be learned about this widely affected population. The same should hold in Africa if sufficient care is invested in the effort.

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Notes:

- ¹ For a complete list of publications and reports see the project website at <http://aidseld.psc.isr.umich.edu/>.
- ² A far more detailed description and assessment of our data collections strategies is available in research report form (Knodel *et al.* 2003).
- ³ Besides the research cited above, there is also a large number of studies dealing with the AIDS epidemic in Africa that provides relevant information about the impact on older persons even

though older persons are not their specific focus. This is particularly true for studies about AIDS orphans and AIDS caregiving. In fact, our knowledge so far about the situation of AIDS parents in Africa likely owes more to such research than it does to the research directed at older people. Some attempt to summarize results from African research is included in Knodel, Watkins, and VanLandingham, 2003.

⁴ For details of these components see Knodel *et al.*, 2003.

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