

The Changing Impact of the AIDS Epidemic on Older-Age Parents in the Era of ART: Evidence from Thailand

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Abstract Previous research makes clear that before antiretroviral therapy (ART), when HIV led to disabling illness and certain death, many older persons as parents of infected adults experienced adverse emotional, material and social consequences. The present study examines how widespread access to ART is transforming the situation in Thailand. Interviews with parents of adult ART recipients reveal that major improvements in the health of their adult children under treatment is associated with major reductions in parental caregiving and expenses associated with their HIV-infected child although parents continue to provide psychological support. Parents own worry about their child's health also declines. Most adult children on ART are able to continue or resume economic activity and many contribute to support of the parental household. ART appears to reduce negative community reaction. Nevertheless, given uncertainty surrounding how long ART can protect against fatal illnesses, whether the adverse impacts of the AIDS epidemic on parents are being eliminated or only postponed remains an open question.

Keywords AIDS and older persons: antiretroviral therapy · HIV/AIDS impact · Parental caregiving · Parents of adults with HIV/AIDS · Thailand

Introduction

Until very recently the onset of HIV related illnesses led to a rapid decline in health followed by virtually certain death in most low- and middle-income countries including Thailand. Although there was some recognition that non-infected adult family members could be adversely affected, attention focused mainly on young children left orphaned. There was little acknowledgement that most adults who became ill had surviving parents for whom the consequences of the illness and death could be very substantial. That the parents were typically at relatively advanced ages likely contributed to their invisibility in the discourse

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surrounding the epidemic given the association of HIV with prime age adults and the more readily apparent vulnerability of young orphaned children. Yet much of terminal stage care, financial costs and psychological stress associated with the illness and death of HIV infected adults was borne by older age parents as clearly documented by research in Thailand and elsewhere (Knodel and VanLandingham 2002; Knodel *et al.* 2003; Knodel *et al.* 2007; Knodel and Saengtienchai 2004; Lee *et al.* 2010; Moore and Henry 2005; Moore 2007; Ssengonzi 2009; Vithayachockittikhun 2006).

More recently, the widening availability of antiretroviral therapy (ART) is radically changing the context of the epidemic. Infected persons can now receive effective treatment to regain reasonable health or even prevent opportunistic illnesses if started early enough. This likely has major implications for the parents of those who access ART, considerably altering the consequences for them. Yet systematic evidence to examine likely changes has been almost entirely lacking. Studies related to ART typically focus on the recipients and rarely consider consequences for family or household members (ADI 2010 and Kaler *et al.* 2010 are notable exceptions). Moreover, none have focused on the older age parents of adult ART patients. The present study aims to fill this gap by exploring how the situation of parents of HIV-infected adults changed as a result of widespread ART access in Thailand by focusing on parental caregiving, psychological support and impact, parental and filial material assistance, and community reaction.

Conceptual Framework

Presumably the impact of ART has been to lessen the adverse consequences for parents and other family members. Conceptual frameworks for analyzing potential pathways through which the illness and death of a HIV-infected adult child could impact older-age parents in low and middle income countries were developed prior to widespread availability of ART (Knodel *et al.* 2003; VanLandingham *et al.* 2000). These frameworks guided the formulation of the research questions addressed in the present study of how ART availability has altered the situation. Figure 1 presents a diagrammatic synthesis of these frameworks. The potential effects are arranged clockwise in accordance with the timeline that they logically follow.

Emotional stress likely pervades all stages of impact and thus is placed at the top of the diagram. Prior to and following diagnosis, especially after the child becomes symptomatic, parents could be impacted economically through the material support provided to their adult child in connection with treatment and living expenses. Time-consuming parental caregiving could not only involve opportunity costs but also place strains on parents' physical health. Moreover adverse community reactions could affect their social lives and perhaps their businesses. The death of the adult child could involve considerable financial costs associated with the funeral. Moreover, material or other support that the child might have provided to the household would be forfeited. If orphaned grandchildren were left behind, the deceased child's parents would often be involved in foster care involving both time and expenses. Finally, in the longer run any future support during old age that would have been expected from the deceased child would no longer be possible.

Setting

Thailand provides a particularly appropriate setting for a study of the impact ART on older-age parents of adult recipients. As in many developing countries, intergenerational

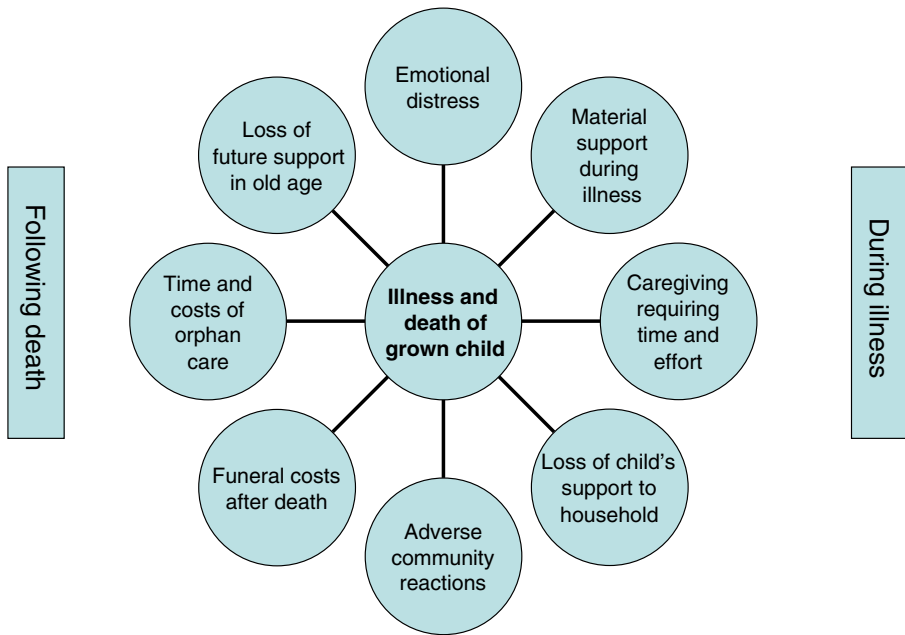


Fig. 1 Potential pathways to adverse impacts of the HIV/AIDS epidemic on parents of infected adults prior to widespread availability of antiretroviral therapy (ART)

exchanges of services and support remain pervasive and flow in both directions, a situation which conditions the involvement of older-age parents and the consequences for them when an adult child contracts HIV. Over 70% of persons age 60 and older live with or near a child and most receive some form of material support from their adult children (Knodel and Chayovan 2009). At the same time, parental concern for the well-being of their children continues even after their sons and daughters become adults. Under these circumstances, it is not surprising that according to research conducted in Thailand prior to the widespread provision of ART, 67% of adults who died of AIDS lived with or nearby a parent and 65% received parental care at the terminal stage of illness. The percentages are even higher if only those who had living parents are considered (Knodel *et al.* 2001). One reason for the high level of parental involvement was that it included a substantial number who migrated earlier but returned to their parents for care after becoming seriously ill (Knodel and VanLandingham 2003).

Thailand was the first Asian country with a significant AIDS epidemic but achieved considerable success in reducing adult prevalence to 1.4% by 2007. Nevertheless, an estimated 520,000 adults and 10,000 children were living with HIV in 2009 (UNAIDS 2010). Thailand is also exemplary in the provision of ART. Starting on a small scale in 2002, almost four out of five persons with advanced HIV infection in Thailand were receiving ART by 2009 (Li *et al.* 2010; UNGASS 2010). Most ART patients are treated at government expense under the universal health coverage or other government insurance programs. Many hospitals that distribute ART established Comprehensive Care Centers that involve support groups of PLHA (persons living with HIV/AIDS) to provide counseling and assist with home visits during which their responsibilities include informing family members about ART (Chasombat *et al.* 2009; Kumphitak *et al.* 2004). Moreover, the 10th National AIDS Plan (2007–2011) for the first time includes older people affected by HIV/AIDS as a specific target group for interventions (Orbach 2007).

Data and Methods

The present study is based primarily on responses to a survey between September 2008 and February 2009 of 108 parents of adults on ART in several sites in each of the four regions of the country. An independent survey between April and November 2008 of 912 adult ART patients (age 18 and older) provides background information that permits placing the sample of parents in broader context.¹ In the case of the ART patient survey, respondents filled out a self-administered one-page questionnaire when they came for resupply of medications at 18 government distribution sites in five provinces and in Bangkok. Response rates were not systematically recorded but nurses at each site unanimously reported that almost every one asked was willing to comply. Although not based on a probability sample, the patient survey covered a wide range of settings and the distribution of respondents resembles the national case load with respect to gender and the sources of government insurance used (Knodel *et al.* 2010). Given these features together with the fact that the vast majority of PLHA on ART receive their supply through the government program, the results are likely to be reasonably representative.

The parent survey used a structured questionnaire with close-ended questions (available at <http://www.phishare.org/documents/AIDSELD/8307/>) suitable for quantitative analysis. Interviews were conducted by graduate nurses who studied at the Chulalongkorn Faculty of Nursing and two faculty members under whom they had studied. The adult child on ART was present at 55 of the interviews and in 24 assisted in answering questions about themselves.² When both parents were present (27 cases) one was designated as the primary respondent (usually the mother) although the other parent could help answer questions. For the total sample, mothers served as the primary respondents for 80% of the interviews.³

The parents interviewed constitute a convenience sample indentified through local PLHA support group members who acted as intermediaries. Since intermediaries' knowledge of parents was limited largely to those of local ART patients, most parents interviewed either lived with the ART patient (82 cases) or in the same locality (13 cases). In almost a fifth of the cases in which the adult child on ART coresided with parents, the child had returned from outside the locality following diagnosis. Moreover, the cases in which the adult child on ART currently lived outside the parents' locality involved a number in which the adult child had coresided but subsequently left to seek work. Thus the recruitment process resulted in a sample of parents who were particularly likely to be involved with their adult child on ART by virtue of physical proximity. Nevertheless, within the broader population of all parents with an adult child on ART, the proportion that lives with or near their child on ART is quite substantial (see below). Thus the results are particularly relevant for this important subset.

Given our interest in comparing the situation before the adult child started on ART and currently (i.e. the time of the interview), selection favored parents whose child had been on ART sufficiently long for impacts to be evident. In about three-fourths of the cases, the adult child had been on ART for at least a year and in only six cases for less than 6 months. Most parents interviewed (71%) lived in rural areas, 22% in small towns, and a few in larger urban areas although none in Bangkok. Most (62%) rated their relative economic position as

¹ The research was approved by IRBs at the University of Michigan and Chulalongkorn University.

² Interviewers did not perceive any problem created by the presence of the adult child on ART. To the contrary it generally contributed to the accuracy of responses to factual questions concerning them.

³ The predominance of mothers as primary respondents reflects their greater availability at the time of interview, the considerably higher widowhood among mothers than fathers, and their more central involvement in caregiving.

average but among the rest more reported their situation as below average (31%) than above average (8%).

In order to evaluate how situations changed following ART, the parent survey included both questions concerning the current situation and retrospective questions about the situation either just prior to treatment initiation or prior to HIV diagnosis (depending on the issue). While recall error is possible, the questions addressed matters that are certain to have been very important to the respondent and unlikely to be forgotten. Moreover, there is no obvious reason why respondents would distort their experience earlier compared to their current situation. The fact that the accounts of their situation prior to ART accord well with previous studies conducted in Thailand before ART access became widespread suggests that recall error is unlikely to have seriously affected results (e.g. Knodel *et al.* 2001; Knodel and Saengtienchai 2004).

Background

Evidence from the ART patient survey indicates that 83% of adults under treatment had at least one living parent. This agrees closely with an earlier study that found 82% of adults who died of HIV/AIDS were survived by at least one parent (Knodel *et al.* 2001). Moreover, almost three-fourths (74%) of the ART patient sample had a living mother. This is important given that prior research shows that mothers are more likely than fathers to provide personal care to HIV infected adult children (Knodel *et al.* 2001). Just over half (52%) of ART patients overall lived in the same locality with a parent including 33% that coresided in the same household. If only those with a living parent are considered, the percentages rise to 63% living in the parental locality including 40% that coresided.

The relatively high proportions of adult ART patients that coreside with parents or live in the same locality at least in part reflects return migration due to illness brought on by HIV (Knodel and VanLandingham 2003). The fact that co-residence appears to be fairly common between ART patients and their parents is important since such a situation considerably enhances the opportunities for parents to provide assistance. It also makes clear that although the parent survey sample in the present study largely consists of cases in which the ART patient coresides or lives nearby, such cases constitute a large share of the overall adult ART patient population.

Although the ART parent survey is based on a relatively small convenience sample, the age and sex distributions of the adult children on ART and their parents are reasonably consistent with those that would be expected based on the results of the ART patient survey. According to the ART patient survey, the median age of adults on ART with a living parent is 37 and just over half (51%) are females. The adult children on ART covered by the parent survey are quite similar in these respects with a median age of 35 and 53% female. Also according to the ART patient survey, 94% of surviving parents of adult recipients were 50 or older, 65% were 60 or older and 26% were 70 or older. Parents covered by the parent survey have a relatively similar age distribution with 97% being 50 or older, 73% 60 or older and 25% 70 or older.

Results

All tables and results reported in this section are based on the parent survey. Given the convenience nature of the sample of parents who were interviewed, tests of statistical significance are not strictly valid and are omitted from the main body of tables. However for their descriptive value, statistical significance levels are summarized in the table footnotes.

Changes in PLHA health In the parent survey, respondents were asked about the overall health status of their HIV-infected adult child prior to starting ART and to what extent the health status had changed since then. Exactly half of the 108 respondents reported that their adult child was in poor health or was seriously ill before starting treatment. Another third reported that there were health problems but not extremely serious ones while the remaining 17% said their child's health was good. The fact that some of the adult children started ART while still in good health reflects the fact that the program admits persons once their CD4 count falls below 200 even if they are asymptomatic (UNGASS 2010).

In over half (56%) of the interviews, parents reported that their adult child's health had improved greatly since starting ART and about a fourth (24%) reported that it improved but that some problems remained. A modest proportion (14%) said that the child's health had not changed much and only a few (6%) said it had worsened. All of the cases in which the patient's health was said to have worsened were among those whose health was good or who had not had serious health problems prior to the start of treatment. Moreover, most that were reported to have little or no change in health status were cases where the health of the child on ART was good when treatment started, thus signifying that reasonably good health was maintained and can be considered a positive outcome.

The interviewed parents were also asked if their adult children experienced a series of 20 specific symptoms typically associated with HIV infection before starting ART and if they currently did so. In some cases the son or daughter in question assisted in answering thus enhancing accuracy. Overall, the average number of symptoms experienced declined from 7.2 to 1.7 between just prior to ART initiation and the time of the interview. With the sole exception of a tiny fraction reporting blindness, the decline in the percentage experiencing a symptom was very substantial typically falling proportionately by three fourths and never by less than by half. Clearly, although ART did not necessarily lead to full recovery of health for those in treatment, it led to very substantial improvements for most that were symptomatic before and enabled most that started treatment prior to becoming symptomatic to maintain their health. This, in turn, can radically alter the situation with respect to the need for caregiving and other consequences for parents and other affected family members.

Parental caregiving As already noted, research conducted prior to the widespread access of ART in Thailand documented that parental caregiving to HIV-infected adults was common and substantial, especially at the terminal stage of AIDS when serious debilitating illnesses occurred. In the present study, the parents interviewed provided information on whether they or their spouses had performed any of 15 specific caregiving tasks before their child started ART and if they were currently doing so. Among the total sample of 108 respondents, 73% performed at least one of the tasks prior to the start of ART compared to 42% who were doing so at the time of interview. Not surprisingly the proportion of parents that provided care is clearly associated with their location relative to their child with HIV. Among the small number of cases in which the interviewed parents lived in a different locality since their child was diagnosed with HIV, the proportion that provided care was far lower than among other cases. This underscores the need when interpreting results of the present study to take into account that the sample of interviewed parents largely consists of those who lived with or nearby the ART patient.

As Table 1 shows, caregiving with respect to each specific task declined considerably after the initiation of ART. Clearly the substantial improvement in the health of many of the HIV infected adult children following initiation of ART relieved parents from much caregiving. Proportionately, the percentages declined by over half for all but two of the 15 caregiving tasks and the mean number of tasks performed by parents fell from 4.2 to 1.6 between the time just prior to the start of ART and the time of the survey.

Table 1 Parental caregiving assistance (by respondent or spouse) associated with HIV infected adult children, before the start of ART and at the time of interview

	Before ART ^a	At time of interview	Absolute change ^b	Proportionate change
% receiving type of assistance				
Personal care assistance				
Help moving around	25%	8%	-17	-0.67
Help bathe	21	5%	-17	-0.78
Help dress	18	5%	-13	-0.74
Help with eating	17%	12%	-15	-0.89
Help go to toilet,	17%	4%	-13	-0.78
Any personal care assistance	30%	9%	-20	-0.69
Daily living assistance				
Prepare food	54%	29%	-25	-0.47
Launder clothes or bed linens	31%	17%	-14	-0.45
Make bed or clean room	24%	9%	-15	-0.61
Any daily living assistance	55%	29%	-25	-0.47
Health care assistance				
Help with medicines	31%	7%	-24	-0.77
Massage	31%	10%	-20	-0.67
Encourage exercise	28%	19%	-9	-0.33
Clean wounds/change bandages	6%	2%	-5	-0.71
Any health care assistance	49%	25%	-24	-0.49
Instrumental assistance				
Accompany to health services	66%	31%	-35	-0.53
Consult with health providers	35%	10%	-25	-0.71
Help apply for benefits	16%	6%	-10	-0.64
Any instrumental assistance	67%	31%	-35	-0.53
Mean number of tasks ^c	4.2	1.6	-2.5	-0.61
Among those who provided care (excluding instrumental care)				
% who spent most of the day giving care	41%	18%	-23	-.57
% who assessed that the caregiving to be very difficult	36%	12%	-24	-.67

Total $N=108$. Differences between before ART and at time of interview are insignificant at the .05 level for encourage exercise and clean wounds/change bandages; are significant at the .05 level for laundering and apply for welfare; all others are significant at .01 level

^a Respondents who indicated that their child was in good health prior to ART were not asked about caregiving at that time with the partial exception of accompanying to health services and are treated as not performing these tasks during the pre-ART period. Since all respondents were asked about caregiving tasks currently, the reduction in caregiving following ART may be underestimated

^b Expressed in terms of change in percentage points for individual tasks and in number of tasks for mean number of tasks

^c For the purpose of calculating the mean, one additional task was attributed to the very small number of respondents who replied positively when asked if they did some "other" caregiving task than those listed

The tasks in Table 1 are arranged in terms of four broader domains of assistance: personal care, daily living activities, health care and instrumental help. Proportionately the largest decline is with respect to personal care. This is logical because these are tasks adults

normally do on their own and the vast majority of the ART patients had regained sufficient health to be able to do such tasks for themselves. With respect to the other domains of caregiving, although very considerably reduced, substantial minorities of parents report they still provide at least some assistance. Some of the tasks, especially those related to assistance for daily living, may not necessarily be associated with the HIV or health status of the adult child but rather done routinely by parents, especially for coresident children. In contrast, the tasks under health care and instrumental assistance are not routine and thus parental assistance is likely related to the HIV status of the adult child and the fact that the child is undergoing ART.

Respondents who provided care for their HIV-infected adult child themselves or whose spouse did either before the child started ART or currently were asked about the time involved and the difficulty experienced providing the care. Since instrumental care, unlike the other forms, is typically done on an occasional rather than a daily or frequent basis, the results referring to the time and difficulty involved are also shown in Table 1 based on only those who gave some kind of care other than only instrumental care. The share of parental caregivers who reported that they spent most of the day giving care fell from over two fifths from the time before their HIV-positive child started on ART to less than one fifth currently. At the same time, prior to the initiation of ART, more than a third reported that the caregiving was very difficult compared to only a little over a tenth at the time of the interview. Thus, ART not only greatly reduced the need for parental caregiving but it also reduced the time and difficulty involved for those parents who were currently still providing care.

Psychological support and impact Parents were also asked if they carried out a number of possible actions to improve the psychological state of their child as related to the child's HIV positive status. As evident in Table 2, over 80% said they gave encouragement, tried to calm the child, chatted together and offered kind words both before ART and currently. Unlike the situation with caregiving, the percent that did these things currently differs only modestly from before their child started ART. The mean number of types of psychological support provided only declined from 5.9 to 5.3 between the two periods. Despite health improving after ART, the need for psychological support presumably remains. This is understandable given that both parents and patients likely realize that ART does not cure HIV and requires strict adherence to be successful.

The improvement in their child's health associated with ART appears to have substantially improved the psychological well-being of parents. Respondents were asked how worried they were about their child's health prior to the initiation of ART and currently. The results, also shown in Table 2, indicate that parents were far more likely to be seriously worried before ART than currently. Those who said they were very or quite worried declined sharply from 72% to 23% while those who said they were not particularly worried increased from 10% to 38%. Nevertheless, their child's health is still a matter of concern for most parents and the majority continues to worry at least somewhat in this regard. Undoubtedly anxiety about their child's future situation continues because of uncertainty about how long the health benefits of ART will persist. Moreover, in some cases children were still experiencing adverse symptoms associated with HIV.

Parental and filial material assistance Research in Thailand before ART was widely accessible found that parents of adults who became sick and died of AIDS often helped pay for medicines, health services, transportation and food during the time of illness. In addition, parents often paid funeral costs and supported orphaned grandchildren both during

Table 2 Parental psychological support (by respondent or spouse) to HIV infected adult children and parental worry about their child's health, before the start of ART and at the time of interview

	Before ART	At time of interview	Absolute change ^a	Proportionate change
Psychological support to PLHA: <i>Respondent or spouse did the following (%)</i>				
Give encouragement	89%	84%	-5	-0.05
Try to calm down	88%	77%	-11	-0.13
Chat together	83%	86%	3	0.03
Offer kind words	82%	81%	-2	-0.02
Try to please	79%	69%	-9	-0.12
Provide company	78%	67%	-11	-0.14
Make merit	57%	42%	-15	-0.26
Go out together	35%	22%	-13	-0.37
Mean number of psychological supports ^b	5.9	5.3	-0.6	-0.11
Psychological impact on parent: <i>Extent worried about child's health (%)</i>				
Very or quite worried	72%	23%	-49	-0.68
Somewhat worried ^c	18%	40%	+22	+2.26
Not particularly worried	10%	37%	+27	+2.64

Total $N=108$. Differences between before and at time of interview are not statistically significant at the .05 level for chat together, keep company, provide encouragement, try to please and offer kind words; go out together and stay calm are significant at the .05 level; the remaining differences are significant at the .01 level

^a Expressed in terms of change in percentage points for individual tasks and in number of tasks for mean number of tasks

^b For the purpose of calculating the mean number, one additional task was attributed to the very small number of respondents who replied positively when asked if they provide some "other" psychological support than those listed

^c Includes a small number who gave a qualified answer

the time of illness and after the death. Such expenses could drain the parents' financial resources and adversely affect their economic situation particularly for those who were especially poor (Knodel and Im-em 2004).

In the interviews with parents of ART patients, respondents were asked about assistance they provided for expenses associated with the situation of their child both before ART was started and currently. As Table 3 shows, the percent of parents who helped pay expenses in each category is noticeably lower at the time of interview than before ART started. Overall the share who helped with at least one type of expense declined from 69% to 44% and the mean number of types of expenses for which parents provided assistance fell by half.

Proportionately, the largest declines in expenses relate to medicines and clinic or hospital fees, both declining by around three fourths. This likely reflects not only that ART is now covered by government insurance in Thailand but also that before ART was initiated episodes of illness associated with opportunistic infections led to transportation, hospitalization and treatment costs. Paying for other types of expenses also declined substantially. The most modest change is in assistance for school expenses for affected grandchildren. This may be because such expenses continue for a considerable period of time and that some grandparents routinely assist with these expenses regardless of HIV or health status of the grandchildren's parents.

Table 3 Parental assistance with expenses (by respondent or spouse) associated with HIV infected adult children, before the start of ART and at time of interview

% of cases in which parents (respondent or spouse) assisted with expenses in stated category	Before ART	Currently	Absolute change ^a	Proportionate change
Food	59%	33%	-26	-0.44
Transportation	56%	27%	-29	-0.52
Clinic or hospital fees	34%	9%	-25	-0.73
School expenses for PHA children	32%	28%	-5	-0.14
Medicine	30%	6%	-23	-0.78
Any of above categories ^b	69%	44%	-25	-0.36
Mean number of categories of expenses with which parents assisted ^b	2.1	1.1	-1.06	-0.50

Total $N=108$. Differences between before ART and at time of interview are not statistically significant for school expenses at the .05 level but are significant at the .01 level for all other expense types

^a Expressed in terms of change in percentage points for individual items and number of items for mean number of expenses

^b For the purpose of calculating any of the above categories and the mean number of categories, one additional type of expense was attributed to the very small number of respondents who replied positively when asked if they provide some "other" type of expense than those listed

Whether or not the adult child worked just before being diagnosed with HIV and if the child had supported the parents' household at that time is shown in Table 4. The time frame shifts to before diagnosis rather than referring to the onset of ART since by the time therapy started some may have already been seriously ill and discontinued work as a result. Over 90% of the adult children on ART were economically active, 70% had helped support the parental household and over two-fifths had been the main supporter just prior to being diagnosed. These high levels of support for the parental household likely reflect in part that the sample largely consists of cases in which the adult children were living with or in the same community as parents. By the time of the interview, the proportion of their children on ART who were working was just under three fourths, over half (56%) were contributing to the support of the parental household and just over one fourth (27%) were the main supporter.

Table 4 Economic activity and parental household support by adult child on ART, before diagnosis and at time of interview

Economic activity of adult child and role in supporting the parental household	Before diagnosis	Currently	Absolute change ^(a)	Proportionate change
Adult child worked	94%	73% ^(b)	-20	-0.22
Adult child helped support household	70%	56%	-15	-0.21
Adult child main supporter of household	44%	27%	-17	-0.38

Total $N=108$. Differences between before diagnosis and at time of interview are statistically significant for work at the .001 level, for help support household at the .05 level and for main support of household at the .01 level

^a Expressed in terms of change in percentage points

^b 63% working fully and 10% working partially

The fact that the current percentages are lower than those prior to HIV diagnosis reflects the fact that not all ART recipients regain full health. Despite this, it is clear that ART allowed most recipients to either continue or resume working and to provide support to the parental household and in some cases major support. Moreover, the health of those recipients who have not fully recovered may improve sufficiently in the future to enable them to work although others may experience relapses. Given the likelihood that in the absence of ART many of the adult children would either be suffering from a disabling illness or have died thus excluding them from being economically active at all, it is clear that this is an important route through which ART benefits many of the parents.

Community reaction Persons on ART and their families live in communities where reactions of neighbors and other community members can either help or hinder their quality of life. Much has been written about the stigmatization of persons with HIV/AIDS including “secondary stigma” that extends to family members and caregivers (Ogden and Nyblade 2005). However, reactions can also be sympathetic and supportive and likely vary across settings and over time. Previous research in Thailand found that while negative community reactions were not absent and may have predominated at early stages of the epidemic, positive reactions are more common recently (VanLandingham *et al.* 2005).

The limited discussions of how ART affects community reaction argue in both directions. Some suggest, including with specific reference to Thailand, that ART reduces stigma and discrimination, as it often eliminates the physical signs of AIDS that trigger negative reactions while others argue that effects of ART on bodily appearance may perpetuate stigma (Ezekiel *et al.* 2009; Lyttleton *et al.* 2007; Maman *et al.* 2009; Wolfe *et al.* 2008). One study in Tanzania suggested that because the provision of ART allows PLHA to continue sexual activity and spread HIV, it leads to blaming recipients (Roura *et al.* 2009). Still others suggest that exposure to stigma and discrimination is increased because ART programmes require disclosure of HIV/AIDS (Apinundecha *et al.* 2007; Liamputtong *et al.* 2009). Regardless of how ART may affect community reactions towards recipients, the impact could quite plausibly extend to their family members including parents, especially those who are involved in caregiving for their infected adult child.

Presumably reactions from others in the community depend on their awareness of the HIV status of the infected person. Thus questions in the parent survey about how community members reacted were asked only if parents indicated that community members (other than immediate family members) knew that their adult child was infected at the time. This meant that 43% of respondents were asked about community reaction prior to ART initiation compared to 76% about the current situation.⁴ The questions asked about three possible positive reactions (sympathy or concern, visits, and receipt of food or other gifts) and about three negative reactions (avoidance of social contact, gossip about PLHA or family, blame for adult child having HIV/AIDS).

Consistent with previous research in Thailand, positive reactions were reported substantially more frequently than negative ones both before the start of ART and at the time of the interview. Prior to ART initiation, two thirds indicated that others in the community visited and showed sympathy or concern about their situation. In about half of the cases, the respondents also reported that they received food or other gifts from neighbors or other community members. The extent of positive reactions was fairly similar at the time of the

⁴ Results reported in the text are based on the full set of respondents who were asked about it in reference to each of the times responses. Results are substantively the same, however, even if the comparison is limited to only to those cases in which community members were aware both before ART and currently.

interview although the proportion who indicated that other community members expressed sympathy or concern increased modestly.

Reports of negative reactions were not lacking, especially prior to ART. Almost a third of parents reported that at that time some community members avoided visiting or contacting them and almost half reported gossip about their child or family. In close to 30% of the cases, the parent reported that others in the community blamed them for their child's illness. By the time of the interview, however, each of these negative reactions was substantially lower and overall under a third reported any of the three negative reactions. Hence the predominance of positive over negative reactions was considerably greater than prior to when their adult child started ART.

Discussion and Conclusions

The present study clearly documents that the spread of ART in Thailand has substantially reduced adverse economic, psychological and social consequences for parents of PLHA. The driving force behind the changed impact is the restoration or maintenance of reasonably good health of their HIV infected adult children following treatment. These health benefits have resulted in major reductions in the need for parental caregiving and assistance compared to when ART was not widely available although parental psychological support for their HIV infected sons and daughters continues to remain common. At the same time, parents' own psychological well-being improved as indicated by a major reduction in their worries about the health of their HIV-infected adult children (see also Rotheram-Borus *et al.* 2010).

The spread of ART also reduced the economic strain on parents of patients. Major reductions occurred in an array of their expenses associated with their HIV-infected child. In addition, prior to widespread access to ART, when HIV-infected adults were destined for premature death, parents not only lost any current support that the infected child may have been providing but also the prospect of future support. Because most ART patients are able to continue or resume economic activity, the situation has substantially changed and many parents receive material support from them and perhaps can anticipate old age support in the future.

ART not only permits the PLHA to be economically active but also frees their parents from most caregiving thereby allowing them to devote time to economic activities that would otherwise be curtailed (Kaler *et al.* 2010). Prior to ART, caregiving could take up most of a parent's day. Although the present study did not directly ask about the impact of ART on the parents' economic activity, prior research in Thailand conducted before ART was widely available documented substantial opportunity costs for parental caregivers (Knodel and Im-em 2004). Thus ART can lead to restoration to work for both the recipient and the caregiver.

ART is also associated with reduced negative reactions from others in the community and thus may also mitigate the social impact of AIDS on parents. Since other changes likely occurred that helped reduce stigmatizing attitudes and beliefs during the intervening period, this reduction cannot be attributed to ART with certainty. Still, the results are consistent with the suggestion that the spread of ART contributes to improved reactions from others rather than the opposite. As the parents reported, ART led to major improvements in their infected adult child's health thus reducing visible symptoms and allowing many to resume reasonably normal lives. These changes quite plausibly reduced concerns about transmission among community members through casual contact with the patient or their family.

Despite these benefits, it would be mistaken to assume that ART has eliminated all adverse impacts of HIV/AIDS on older-age parents of the patients outlined in the conceptual

framework presented above. Although ART appears noticeably to reduce the economic burden on parents, some may have sold assets and even land to cope with their adult child's illnesses prior to treatment. Full restoration of economic well-being thus may not occur if resources that cannot be regained easily such as land or important productive assets have been depleted. This likely varies by setting and with the economic circumstances of the family. The present study did not address this issue but earlier research in Thailand found that only a modest minority of parents who helped with expenses of a HIV infected child sold assets (Knodel and Im-em 2004). In contrast, research in Cambodia and Uganda indicated that this was far more common (Kaler *et al.* 2010; Knodel 2008).

More generally, it is important to recognize that considerable variation characterizes the experiences of parents with regards to the extent that their situation improved reflecting among other things individual differences in the success of ART treatment on their HIV infected adult children. In addition, ART carries risks of serious side effects which not only the patient but also close family members need to deal with. Moreover, it is still uncertain how long the health benefits of ART can last and hence how long the reduced burden on parents and other family members of ART patients can be sustained. It is encouraging that short term survival rates in Thailand are high with 1 and 2 year survival rates at 91% and 87% (UNGASS 2010). Also medical advances may improve treatment in the future. Still, if ART only postpones the debilitating illnesses of those being treated, the parents may need to deal with the situation at even more advanced ages than was the case prior to ART.

Given these uncertainties, it is unsurprising that a substantial share of parents still express some worry about the future health of their children on ART. Now that the National AIDS Plan in Thailand acknowledges that older persons affected by the epidemic are a vulnerable group and presumably deserve attention in impact mitigation efforts, serious consideration needs to be given to the provision of psychological support and counseling for them and to ensure that they are correctly informed about ART.

The present study has a number of limitations. The sample of parents on which most findings are based is one of convenience, modest in size and consists largely of those who live in the same locality as their adult child on ART. Future research needs to examine how the spread of ART has altered the consequences of the epidemic for parents who reside at some distance from their HIV-infected children. In addition, not all potential consequences have been addressed in the current study. One omission is the impact of ART on the role of parents in fostering grandchildren of PLHA. Presumably this has been reduced since fewer grandchildren are being orphaned. Nevertheless grandparents may be playing alternative roles especially in cases where the health of the ART patient is not fully restored. This is another important topic for future research.

Despite these limitations, as the first study to focus specifically on how widespread availability of ART altered the impact of the AIDS epidemic on parents of HIV infected adults, it contributes substantively to our understanding of how the epidemic affects older persons. Although based in Thailand, it is likely that many of the findings, at least in broad outline, characterize numerous other settings in the developing world where family care involving older-aged parents is common. While the impact will be conditioned by variation among settings, the limited research that does exist so far suggests there are also likely to be a number of similarities (e.g. ADI 2010; Kaler *et al.* 2010). Hopefully future studies will provide a fuller picture on the changing situation of older persons in the context of the AIDS epidemic.

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