

**The Role of Parents and Family Members in ART Treatment Adherence:  
Evidence from Thailand**

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**Abstract**

High levels of treatment adherence are crucial for the success of expanding anti-retroviral therapy (ART) treatment programs everywhere. Augmenting adherence through treatment supporters is one promising strategy. Most discussions focus on peers, especially members of persons with HIV/AIDS (PHA) groups, for this purpose. Far less attention is given to family members, and older age parents are almost never specifically mentioned. Yet in many settings, ART recipients often live with or nearby parents and other family members who are highly motivated to ensure the treatment's success. This report examines the extent that family members, especially parents, are involved in assisting adherence in Thailand based on results from self-administered questionnaires from 912 adult ART recipients in 18 sites throughout the country. Results indicate that most ART patients live with family members and over 60% live with or in the same locality as a parent. Family members, including parents, commonly assist ART patients to remember to take their medications, particularly if they are in the same household. Moreover, parents often remind adult sons and daughters to go for resupplies and sometimes bring or accompany them to their appointments. The results underscore the need to incorporate close family members, including parents, more explicitly into programs intended to augment adherence and to facilitate their effectiveness as long-term adherence partners by providing them with adequate information, training and resources. Peers from community based PHA groups can be a particularly valuable and appropriate asset in this regards. These findings are relevant not only for Thailand but for the many settings where ART recipients are similarly closely linked to other family members through living and caregiving arrangements.

## **Introduction**

Universal access to affordable anti-retroviral therapy (ART) for HIV infected persons is a high priority endorsed by the UN and major donor agencies. Substantial progress is being made towards this goal in low- and middle-income countries with almost 3 million recipients by the end of 2007, representing a 10-fold increase in only six years. Moreover, in some countries, including Thailand, coverage already exceeds 50% of those in need of ART (UNAIDS 2008). At the same time, strict life long treatment adherence to drug regimes is essential to sustain the health benefits and minimize drug resistance associated with treatment failure. Successful ART provision thus requires not just medical attention but also long term social and psychological support, including encouraging and monitoring adherence (Beals et al. 2006; Hope & Israel 2007). Ensuring that medications are taken regularly and on time and that appointments for resupply and essential tests are kept over prolonged periods of time poses a major challenge both for persons with HIV/AIDS (PHA) themselves and the programs providing treatment. Clearly the success of the continuing roll out of ART depends on developing appropriate, feasible and affordable approaches to facilitating long-term adherence within the financial constraints of resource-limited countries (UNAIDS 2008; Van Damme, Kober & Kegels 2008).

Community-based efforts engaging treatment supporters are a promising approach towards facilitating adherence. Such an approach, often labeled 'buddy programs', typically emphasizes the involvement of peers and implementation through organized PHA self help groups (Burrage & Demi 2003; Hope & Israel 2007; Marino et al. 2007; UN 2008). While there is also recognition that family members provide home care and can play supportive roles in relation to treatment adherence, their importance is rarely stressed (e.g. Ogden, Esim & Grown 2006). Moreover, the potential of parents of adult PHA, who are often of advanced ages, to assist has received virtually no attention (see e.g. Hope & Israel 2007; Nischal, Khopkar & Saple 2005; Mills et al. 2006; UNAIDS 2008; Ware et al. 2009; for a notable exception see Williams et al. 2008). In addition, almost no research has focused on the specific role of family caregivers in promoting or facilitating adherence (Beals et al. 2006)

Sustained assistance with treatment adherence on a prolonged and frequent basis is far more practical if a treatment supporter lives with or very nearby the person on ART and has strong ingrained motivation to help. In these respects, close family members, including older age parents, are particularly appropriate. In many countries, living arrangements of adults often involve residing with or nearby parents and other close relatives. Spouses, children, and siblings typically have much at stake emotionally and often practically when one among them becomes HIV infected and ill. Parents in particular are likely to have deep-seated motivation to ensure their grown children's well-being (Saengtienchai & Knodel 2001). In addition, as grandparents, they often inherit responsibility for grandchildren who are AIDS orphans (i.e. the young children of their sons and daughters who die of AIDS), some of whom have been HIV infected through perinatal transmission (UNICEF 2006). The potential for parents to play an important role is

further suggested by previous research documenting their frequent involvement in caregiving to HIV infected adult children (Knodel & VanLandingham 2002; Knodel, Watkins & VanLandingham 2003). In this study, we examine the extent to which family members, and especially older age parents, assist with treatment adherence among adults undergoing ART in Thailand.

### **The Thai Setting**

***Intergenerational relations.*** In Thailand, as in many developing countries, intergenerational exchanges of services and material support remain pervasive. A norm of filial obligations underlies Thai inter-generational relations (Knodel, Saengtienchai & Sittitrai 1995). At the same time, parents feel obligations to ensure the well-being of their adult children. Thus inter-generational support and services flow in both directions. Living arrangements of older age parents and adult children are closely linked to this system with most older Thais either residing with or nearby at least one adult child (Knodel & Chayovan 2008). According to a 1995 nationally representative survey, approximately half of the adult children of Thais aged 50 and over lived in the same locality as their parents, and half of these coresided with parents (Knodel & Saengtienchai 2004). Increased migration of adult children has reduced this proportion in recent years but still the share of adults who live with or near parents undoubtedly remains large. Moreover, the vast majority of adult children who live elsewhere maintain close contact with parents (Knodel & Chayovan 2008; Knodel et al. 2007).

Under these circumstances it is not surprising that research in Thailand, conducted prior to the widespread provision of ART when AIDS led to virtually certain death, found that the majority of adults who died of AIDS lived with or nearby a parent and received parental care at the terminal stage of illness (Knodel et al. 2001). This included a substantial proportion of PHA who migrated earlier but returned to their parents for care after becoming severely ill (Knodel & VanLandingham 2003)

***The Thai AIDS program.*** Thailand was the first Asian country with a significant AIDS epidemic. Despite considerable success in adult prevalence from a peak of just over 2% in the mid to late 1990s to 1.4% by 2007, 600,000 adults and 14,000 children were living with HIV in 2007 (UNAIDS/WHO 2008). At the same time, Thailand is exemplary in the provision of ART. By 2007, more than half of PHA judged to be in need were receiving treatment which is available at no cost at over 1000 sites through several government insurance schemes. In 2007, 70% of government insured patients were covered under the universal coverage scheme run by the National Health Insurance Office, 22% were insured through the social security system which covers most formal sector employees, and 8% used civil service insurance. The number of private patients receiving ART is unknown but is typically assumed to be around 10,000 (National AIDS Prevention and Alleviation Committee 2008; UNAIDS/WHO 2008).

In 2002 a project designed to encourage adherence through PHA peer support groups was initiated in which at least two members per group would do counseling and make home visits for a modest rate of pay. Among other things, the home visits were intended to provide appropriate information to family members about the importance of adherence (Kumphitak et al, 2004). The PHA are typically affiliated with hospitals that distribute ART and generally are part of “continuum of care centers”. Expansion of the program is underway. Most discussion of augmenting ART adherence in Thailand, including an extensive World Bank report, focus almost exclusively on the role of PHA groups and peer assistance with little mention of the potential role that family members could play (Kumphitak 2004; National AIDS Prevention and Alleviation Committee 2008; Revenga et al. 2006).

## Methodology

Data for the present study were collected through a short anonymous self-administered questionnaire (provided as an Appendix to this report) given to ART patients when they came for resupply at 18 hospital sites in five provinces and Bangkok. The questionnaire was extensively pretested to ensure it was readily comprehensible, was easy to fill out, and could be completed in a few minutes. The selection of sites involved two stages, first choosing provinces and then sites within each province. The design called for including Bangkok and at least one province in each of the four major regions of Thailand to ensure geographic diversity. Two provinces in the north were selected because of distinctive difference in past HIV prevalence in the upper and lower portions.<sup>1</sup> A target of approximately 150 cases per province was set to be divided among the provincial hospital and two community hospitals. Provincial hospitals typically serve the largest number of ART patients in each province. The community hospitals were purposively selected within a province giving preference to those with larger ART case loads while also choosing ones located at different distances from the provincial capital.<sup>2</sup> The number of target cases per site within a province was roughly proportional to the site’s case load. In Bangkok, only two hospitals were chosen since the case loads were very high in each. Overall, 912 adults age 18 and over completed questionnaires, 423 from district level hospitals, 332 from main provincial level hospitals, and 157 from the two Bangkok hospitals.

Data collection took place between April and November 2008. Nursing staff at the hospitals were asked to distribute questionnaires to adult ART patients who came for their monthly resupply during a period not to exceed a month in order to avoid the possibility of the same patient filling out more than one questionnaire. The nurses were instructed to explain the purpose of the study and emphasize participation was entirely voluntary. Information collected concerned the age and sex of the patient, the living status, age and location of their parents, whether the parents knew about the patient’s treatment, and if they

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<sup>1</sup> The provinces were Rayong, Surat Thani, Ubol Rachathani, Pitsanaluk and Lampang.

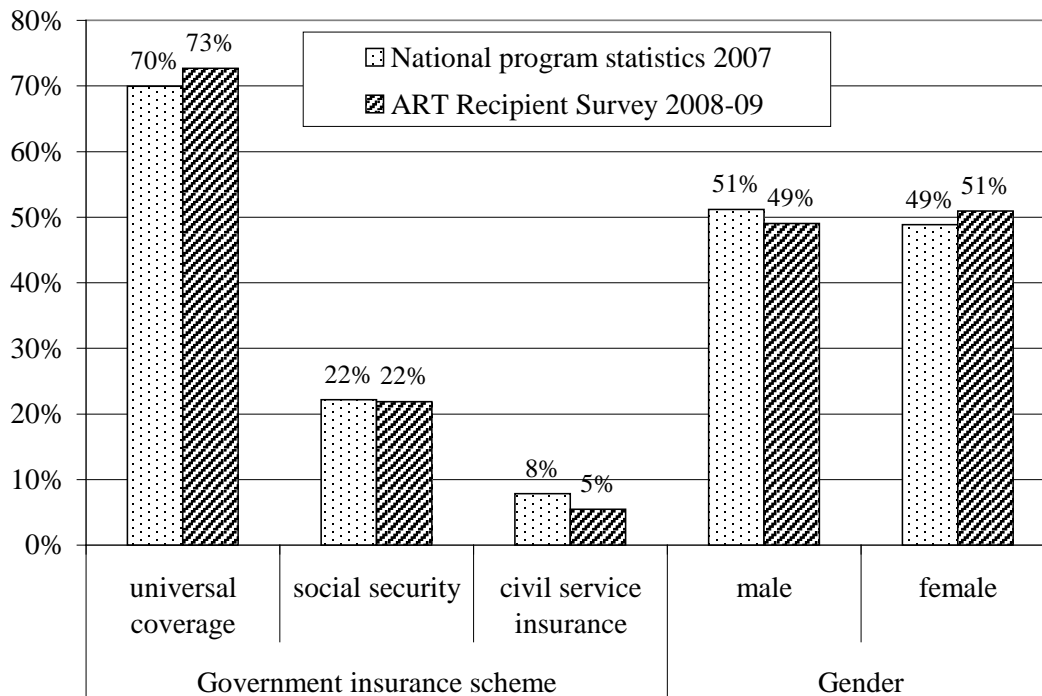
<sup>2</sup> In one province, a third community hospital was included to compensate for insufficient cases available at another originally selected.

assisted in several ways with the treatment. The patient was also asked with whom they lived and if persons other than parents helped remind them to take their medications.

Response rates were not systematically recorded but nurses at each site were asked to summarize roughly how many patients declined to complete the questionnaire. The nurses unanimously reported that almost every one asked was willing to complete the questionnaires. The high response rate is likely explained by the very short length of the questionnaire, the lack of sensitive questions, and the generally good relations the nurses had with patients in the program.

Although the design does not result in a strict probability sample, major segments of the population of adult ART patients are represented by including Bangkok and provinces in all regions as well as both urban and rural sites within provinces. As figure 1 indicates, comparisons with the national pool of ART patients as represented in the government program statistics regarding source of insurance coverage and gender indicate close correspondence with our sample.

**Figure 1.** Comparison of national government program statistics and ART Recipient Survey with respect to type of government coverage and gender of recipient, Thailand



*Sources of national program statistics:* Government insurance data from National AIDS Prevention and Alleviation Committee (2008), annex 2; gender data from the Ministry of Public Health.

*Notes:* Universal coverage refers to coverage through the National Health Insurance Office. ART recipients not using government insurance are excluded. Government data on gender are preliminary. Results for the ART Recipient Survey exclude 46 cases who received treatment outside the government insurance schemes and 6 cases who did not indicate the source.

## Sample description

**Parents and spouses.** Of persons likely to be highly motivated and in a position to assist an adult PHA on a long time basis, parents and spouses are particularly pertinent. The large majority of ART patients in Thailand and likely elsewhere with significant treatment programs have a living parent. Among our sample, 83% reported having at least one parent alive and half of these (42%) had both parents alive. Given that previous research indicated that mothers are more likely than fathers to provide personal care to HIV infected adult children (Knodel et al. 2001), it is significant that almost three-fourths of ART recipients still had a living mother. Many of the parents were in older ages. Only 6% were under 50, almost two thirds 60 and older, and just over one fourth (26%) 70 or older.

Over half of all ART respondents either lived with or near a parent (33% coresided and another 19% lived in the village or urban neighborhood). Among those with at least one parent still alive, 62% lived with or in the same locality as the parents. Just over half of the sample had a live-in spouse or partner.<sup>3</sup> A few respondents may be referring to a same-sex partner or some opposite sex partner who is not considered as a spouse. However, in the Thai context, the vast majority who answered affirmatively were likely to be in an in-tact marital relationship, even if the marriage was not officially registered (Chayovan 1989). Those without a live-in spouse or partner were twice as likely to live with a parent than those without one (46% vs. 22% of all respondents). Together, almost three-fourths (74%) of adults on ART in the sample lived either with a spouse (or partner), a parent, or both.

**Characteristics of ART recipients.** Table 1 shows characteristics of adult ART recipients in our sample according to the location of the ART distribution site type.<sup>4</sup> District hospitals are usually in district towns surrounded by rural areas while provincial hospitals are in the much larger urban administrative capital. Patients accessing ART under the universal coverage scheme are generally required to obtain their supply at the nearest hospital. In contrast, patients under social security typically need to go to a provincial or Bangkok hospital for ART. Those under civil service insurance have the widest choice. Since most rural recipients are under the universal coverage scheme, they are largely limited to district hospitals. In contrast, patients at provincial and Bangkok hospitals are far more heavily weighted towards those residing in urban areas, either in the provincial capital or Bangkok respectively, regardless of the coverage they use. As a result, the vast majority of district hospital patients are under the universal coverage scheme compared to a far smaller majority of provincial hospital patients and only a modest minority of Bangkok hospital patients.

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<sup>3</sup> The questionnaire did not distinguish between these relationships.

<sup>4</sup> Since the sample is largely purposive, statistical significance measures (p-values) should be considered only as a rough guide.

**Table 1.** Characteristics of ART patients

	Location of ART distribution site				p-value
	All ART patients	District hospitals	Provincial hospitals	Bangkok hospitals	
N of cases (total/with living parent) <sup>(a)</sup>	912/755	423/430	332/280	157/135	--
% using UC insurance <sup>(b)</sup>	69.0	95.3	59.2	17.6	.000
% male	49.1	42.5	52.9	58.6	.001
Age (% distribution)					.520
18-29	9.3	9.6	14.3	10.3	--
30-34	21.4	23.2	16.9	21.3	--
35-39	29.0	27.2	24.7	27.6	--
40-44	22.1	19.8	21.4	21.2	--
45-49	10.5	13.3	10.4	11.5	--
50+	7.6	6.8	12.3	8.1	--
Total	100	100	100	100	--
Mean age <sup>(c)</sup>	38.5	38.4	38.2	39.1	n.s.
% having a living parent	82.8	80.4	84.3	86.0	.182.
% living with					
parent	33.3	34.4	33.9	29.0	.455
spouse/partner	51.6	54.1	52.7	42.7	.044
children	31.7	39.2	28.0	19.1	.000
sibling	14.0	12.3	11.7	23.6	.001
other relative	11.0	9.7	11.1	14.0	.333
other person	4.4	2.8	5.1	7.0	.067
no one (lives alone)	7.8	5.4	9.0	11.5	.031
Location of parents among those with a living parent (% distribution)					.000
same household	40.3	42.9	40.4	33.8	--
same locality	22.9	31.1	18.9	10.5	--
elsewhere	36.7	26.0	40.7	55.6	--
Total	100	100	100	100	--

Source: 2008 ART Recipient Survey

Notes: (a) numbers include small numbers of cases with missing values on several variables shown.

(b) UC refers to universal coverage scheme through the National Health Insurance Office. 6 cases of unknown insurance are excluded but 46 cases not using government insurance are included in denominator. Thus the percent using UC is lower than shown in Figure 1 which is based only on cases using government insurance.

The distributions of patients sampled in the three types of sites differ by gender but not age. Female patients predominate in the district hospital sample, males in the Bangkok sample, while men and women are fairly equally represented in the provincial hospital sample. In all three sites the modal age group is 35-39 with the mean age 38-39. Only small shares of recipients are as old as 50 or younger than 30.

Both the percent of adult ART patients with a living parent and the percent that live with a parent vary only modestly by distribution sites. Bangkok hospital patients are substantially less likely to live with a spouse or partner than district or provincial hospital patients. ART recipients at district hospitals are by far the most likely to live with children while those in Bangkok the most likely to live with a sibling. Overall almost a third of ART patients live with a child. Given the ages of ART patients, many of their children are likely to be old enough to comprehend the basic aspects of treatment and the need for adherence if explained to them. Few ART patients live alone although this is most common in Bangkok and least for patients at district hospitals.

The bottom panel of Table 1 shows where parents of the ART patients are located among those with at least one living parent. Some difference is evident by type of distribution site. Patients at district hospitals are most likely to have a parent locally available while those in Bangkok least likely.

### **Treatment Assistance**

**Who reminds.** In order to assess the role of family members and others in assisting with treatment adherence, respondents were asked to indicate if different types of persons helped remind them to take their medicine. Respondents were also asked to indicate how often parents reminded them to take medicines and whether or not parents reminded them to get resupplies, taken them to get resupplies, helped prepare medicines, and if the parents knew they were on ART.

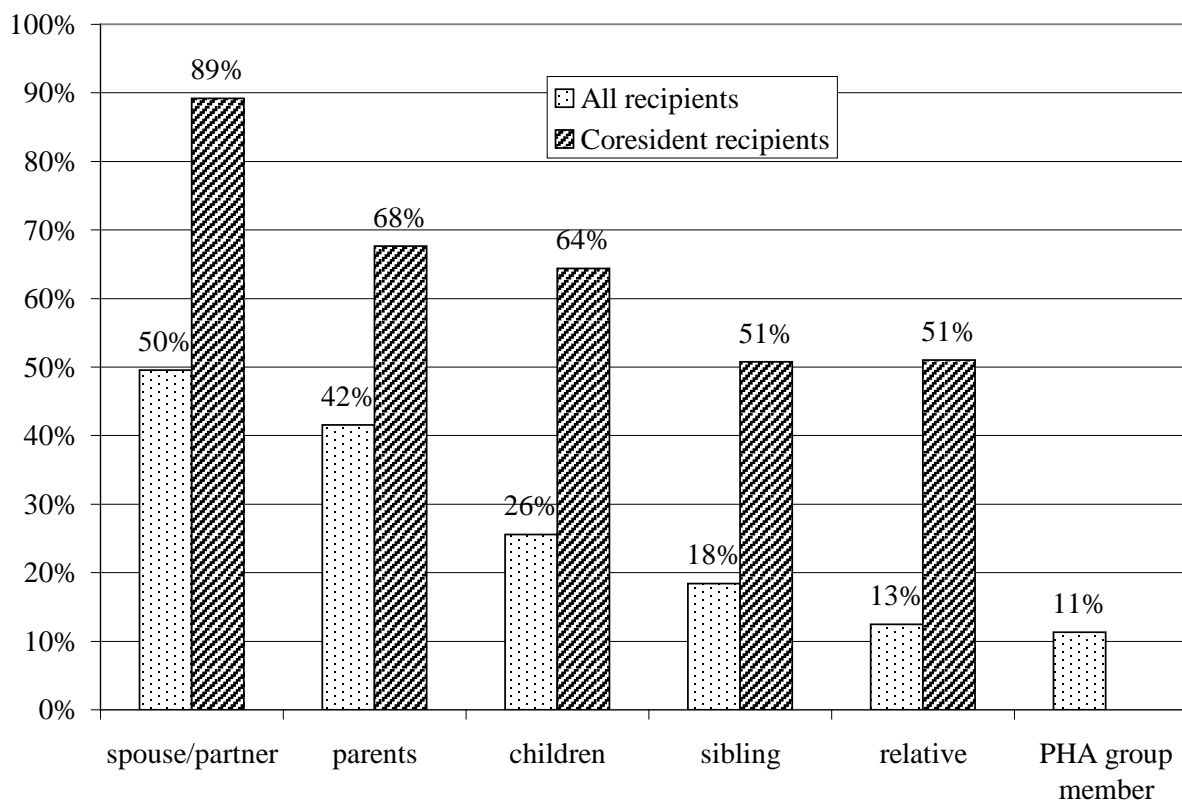
Figure 2 shows the percent of different types of persons who reminded the respondent to take medications. Since coresidence greatly facilitates the ability to do so, results are shown both for the total sample and conditioned on living in the same household.<sup>5</sup>

Among all respondents, 50% indicated a spouse or partner reminds them to take their ART medications and 42% that parents do. These are the two most frequent family members mentioned in this respect. The shares of respondents who mention each of the other types of family members are considerably lower. When results are conditioned on coresiding in the same household, large proportions of coresident family members regardless of relationship are said to help in reminding the PHA to take ART suggesting substantial concern on their part for the well-being of the respondent. Coresident spouses/partners and parents are still the most common persons to remind respondents to take ART medications but coresident children are not far behind. Since the question for persons other than parents does not specify the frequency of reminding, however, in some cases it may be only very occasional.

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<sup>5</sup> Except for parents information is based on a yes-no question that presumably refers to the present situation. For parents, the question asked how often a parent reminded. For Figure 2, responses “never reminded” and “used to but not now” are treated as not currently reminding and all other responses as currently helping remind.

**Figure 2.** Percent who currently remind PHA to take medications among all adult ART patients by relationship to PHA and coresidence status, Thailand



Source: 2008 ART Recipient Survey

Respondents were also asked about PHA group members helping to remind them to take their medications. Overall only 11% indicate that this is the case. This may understate the importance PHA members in the adherence process for at least two reasons. First, assistance by PHA group members may focus on checking up and assisting during the crucial initial stage of treatment and thus might not be mentioned as the questionnaire item implicitly refers to the current situation. Second, PHA group members likely concentrate on persons with difficulties adhering rendering their contributions disproportionately greater than implied by the relatively low prevalence level (Revenga et al. 2006).

**Parental assistance.** As Table 2 shows, almost three-fourths of respondents with a living parent report that their parents are aware that they are on ART but this varies by parents' location. Coresident parents are by far most likely to be aware and those who live in a different locality the least likely. Also older age is associated with lower levels of awareness. Still even among respondents whose parents lived in a different locality and those whose parents are 70 and older, more than half (58% and 62% respectively) indicated that their parents knew they were receiving ART.

**Table 2.** Awareness of treatment and treatment assistance provided by parents, by location of parent and age of youngest parent, among respondents with at least one living parent

	Total	Location of parents			p-value	Age of youngest living parent			p-value
		Co-resident	Same locality	Else-where		Under 60	60-69	70+	
N of cases <sup>(a)</sup>	742-755	299-301	166-171	267-274		275-280	270-274	196-200	--
% whose parents know PHA is on ART	72.5	86.3	72.2	57.9	.000	79.1	73.5	62.3	.000
How often parent reminds PHA to take medicines (% distribution)					.000				.000
daily/almost daily	14.8	24.7	9.0	7.1	--	21.5	12.2	9.2	--
often but not daily	10.4	12.3	9.0	9.0	--	12.4	10.4	7.7	--
sometimes	25.9	30.7	30.1	18.4	--	26.2	28.1	22.4	--
used to but not now	10.2	8.3	10.2	12.4	--	8.4	11.1	11.7	--
never	38.7	24.0	41.6	53.2	--	31.6	38.1	49.0	--
total	100	100	100	100	--	100	100	100	--
Other assistance by parents									
% ever reminded to get medicines	44.4	57.5	38.6	34.3	.000	47.5	47.1	36.5	.031
% ever taken to get medicines	18.8	23.6	16.4	15.0	.020	25.4	19.3	9.0	.000
% ever had medicines prepared	7.2	10.0	4.1	5.8	.034	8.2	8.0	4.5	.234
% had parents do any of the 3 tasks	54.2	70.8	47.4	40.5	.000	62.9	53.6	43.0	.000
Parental treatment assistance score <sup>(b)</sup>	1.58	2.04	1.37	1.19	.000	1.84	1.60	1.18	.000

Source: 2008 ART Recipient Survey

Notes: (a) the total includes a small number of cases either whose age of youngest parent or location of parents is unknown. The range in number of cases reflects the variation in numbers with non-missing data for the specific variables under consideration.

(b) see text for explanation of parental treatment assistance score

Results in table 2 also indicate that parents commonly assist with some form of treatment adherence assistance. Overall among ART patients with a living parent, one-fourth report that parents remind them either daily or often to take the medications and another fourth that parents remind them sometimes. An additional 10% reported that parents used to remind them but no longer do so, presumably because they no longer need reminding. Thus all together 61% indicated parents helped them remember to take their medications either currently or in the past. At the same time, respondents who coreside with parents and those with the youngest parents are far more likely than those whose parents live in a different locality and whose parents are 70 or older to receive such assistance.

Besides remembering to take medicines on time, adequate adherence also involves getting resupplies on a regular basis and preparing the medicines to be ready to take. Over two-fifths (44%) of respondents with a living parent reported that a parent had reminded them to get their resupply and almost a fifth (19%) that parents had taken them to get the medicines. A far smaller proportion (7%) indicated parents helped prepare the medications, presumably because the preparation is simple or unnecessary.<sup>6</sup> In total, 54% of respondents with a living parent indicated they had received parental assistance in at least one of these three ways. As with being reminded to take medications, chances of such assistance are higher if parents coreside or are younger.

Table 2 also provides a summary score for parental treatment assistance. One point is given for each of the three tasks mentioned in the previous paragraph for which assistance is provided, two points if parents currently remind often or daily, and one point if parents currently remind sometimes or did so in past. Thus the score can vary from 0 to 5 with higher scores indicating greater parental assistance. The overall mean score is 1.58 but there is a clear positive association with the proximity of parents and a negative association with age of parents.

Based on this score, Table 3 examines parental treatment assistance within a multivariate framework using multiple classification analysis (MCA). Results are presented both unadjusted and statistically adjusted (i.e. net of the effects of the other variables). Although some parents may be aware that the PHA is taking medications and assist in adherence without knowing that the medications are for ART, being aware that the PHA is on ART is likely crucial for more meaningful parental assistance. Thus results are provided not only based on all respondents with a living parent but also restricted to those whose parents know that the respondent is on ART.

In both sets of adjusted results, the age and sex of the respondent and whether or not they have a live-in spouse or partner show relatively weak associations with parental assistance once other variables are taken into account. The net association between parental assistance and a live-in spouse or partner virtually disappears when results are limited to cases where parents are aware of ART. Thus although spouse or partners frequently help remind ART patients to take medications, their doing so does not reduce the extent that parents promote treatment adherence.

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<sup>6</sup> The most common treatment consists of taking a single pill twice a day, twelve hours apart.

**Table 3.** Mean parental treatment assistance score, unadjusted and statistically adjusted by multiple classification analysis (MCA), among respondents with at least one living parent

	All cases with a living parent		Cases with a living parents aware of the ART	
	Unadjusted	Adjusted (Significance level)	Unadjusted	Adjusted (Significance level)
Sex of PHA		(n.s.)		(n.s.)
Male	1.63	1.63	2.16	2.13
Female	1.54	1.54	1.94	1.97
Age of PHA		(+)		(n.s.)
18-29	1.97	1.77	2.55	2.36
30-34	1.66	1.51	2.14	2.04
35-39	1.42	1.40	1.89	1.87
40-44	1.68	1.74	2.03	2.09
45-49	1.53	1.79	1.96	2.22
50+	1.00	1.50	1.45	1.68
Type of hospital		(n.s.)		(**)
community	1.67	1.62	1.89	1.89
provincial	1.62	1.62	2.19	2.17
Bangkok	1.32	1.42	2.33	2.38
Has live-in spouse/partner		(n.s.)		(n.s.)
no	1.79	1.67	2.10	2.02
yes	1.40	1.51	1.98	2.07
Location of parent		(***)		(***)
same household	2.06	1.99	2.28	2.27
same locality	1.36	1.38	1.77	1.87
elsewhere	1.19	1.26	1.86	1.80
Age of youngest parent		(***)		(**)
under 60	1.84	1.78	2.23	2.15
60-69	1.63	1.66	2.10	2.15
70+	1.16	1.21	1.61	1.67
Which parent is alive		(***)		(**)
both	1.82	1.71	2.20	2.12
mother only	1.49	1.58	1.99	2.08
father only	0.76	0.99	1.21	1.37

Source: 2008 ART Recipient Survey

Significance levels (*p*-value): n.s.= > .10; += ≤ .10 \*= ≤ .05; \*\*= ≤ .01 \*\*\* = ≤ .001.

Note: See text for explanation of parental treatment assistance score

Statistically significant net effects are evident in both sets of results for the relative location and age of the parent and for which parent is alive.<sup>7</sup> Patients whose only living parent is a father receive distinctively less assistance than if only a mother is alive or if both parents are alive. This finding, together with earlier research that found mothers contributed more to personal care of adult PHA who died than fathers underscores the traditional gender roles in Thailand that assign greater responsibility for personal caregiving to women (Knodel et al. 2001). Differences between coresiding with a parent and having a parent in the same locality as well as having a parent under age 60 and one in their 60s is reduced somewhat once cases where parents are not aware that the respondent is on ART are removed from consideration. This suggests that greater hesitancy of respondents to share knowledge of their situations with parents if they live separately or if the parents are at more advanced ages may prevent parents from otherwise assisting.

The results also suggest that hesitancy to be open with parents about their situation is particularly a barrier to parental help for ART patients in Bangkok. When all respondents with a living parent are considered, Bangkok patients report lower scores for parental assistance than patients elsewhere. But when respondents whose parents are not aware of their treatment are excluded, the mean score is actually highest for Bangkok patients.

## **Discussion and Conclusions**

Assuring high levels of treatment adherence is a major challenge facing expanding ART treatment programs in both richer and poorer countries. Augmenting adherence through enlisting peers, especially members of PHA groups, to serve as treatment partners is clearly a promising strategy in many contexts including Thailand (Marino et al. 2007; Revenga et al. 2006; UNAIDS 2008). While such programs are likely cost-effective, they typically entail administrative expenses and payments for those involved which in resource-limited settings where funding is tight can be a matter of concern, especially as ART programs expand.

Although family members are sometimes mentioned in the context of treatment support programs, they receive far less attention than peers. When they are mentioned, distinction is rarely made in terms of relationships to the person on ART. In particular, parents are almost never specifically cited. Yet parents are highly motivated to ensure the health of their adult children and often live with or near their adult child on ART in many settings with significant AIDS epidemics.

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<sup>7</sup> The statistical significance levels shown are only a rough guide given both the purposive nature of the sample and the ordinal level of measurement of the parental assistance score.

The neglect of parents' potential to assist is likely related to their older ages. Health professionals may assume that older persons, who in poorer countries typically have low levels of formal education, are incapable of sufficiently understanding ART to provide useful assistance. A recent study in Cambodia, however, provides evidence to the contrary. Despite little education, parents exhibited considerable understanding of ART and strong motivation to ensure proper adherence by their HIV infected adult children (Williams et al. 2008).

The present study in Thailand provides clear quantitative evidence that most adult ART patients live with close family members and over half live with or in the same locality as a parent. The results also document that family members, including older age parents, commonly assist ART patients to remember to take their medications, particularly when they are in the same household. Parents also assist in other ways, including reminding their adult children to go for resupplies of medications and bringing them to their appointments.

The relative lack of attention given to family members in augmenting adherence is unfortunate. First, given the need for sustained lifetime adherence, family members who live with or nearby ART patients are ideally positioned to provide sustained assistance over long periods of time. Second, such family members are present not only on a day-to-day basis but also often at the specific time that medications need to be taken. Third, close family members typically have deep emotional reasons for wanting the ART patient to achieve and maintain restored health. Finally, they neither require nor expect to be paid to assist. The only costs involved would be associated with providing sufficient information and training to enable them to carry out their assistance effectively.

In most cases, it is unrealistic to expect PHA peers to assist on the same frequent and continuous basis that family members could. Still, home visits by PHA peers can play an important role in providing the information and training to facilitate family members' effectiveness in providing treatment adherence support. PHA peers can also provide other critical supplemental support including occasional monitoring of the family's situation and acting as intermediaries between the family and the health system, especially where PHA support groups are associated with hospitals as in Thailand.

Lack of awareness on the part of family members that a PHA is on ART greatly limits their ability to support treatment adherence although it does not necessarily prevent it. For example, a parent may believe adherence is important even without realizing the medication is ART and that the cause of their child's illness is other than HIV. Thus barriers that prevent PHA from revealing their situation to parents and other family members need to be better understood and addressed. Most likely, concealing ART treatment is related to a sense of shame even in Thailand where stigma has been greatly reduced and supportive community reaction is relatively common (VanLandingham, Im-em & Saengtienchai 2005).

Programs to promote treatment adherence need to be tailored to the social and cultural context in which they are implemented (Russell et al. 2007; Sankar et al. 2006; Ware, Wyatt & Bangsberg 2006). This includes taking account family relationships and living arrangements. Recommendations about the best approaches based on research in the developed countries may well be far less appropriate in the context of the developing world (Mills et al. 2006). In comparison with more affluent countries, the Thai setting shares important features with many other developing countries that are critical for understanding the potential role of family members in assisting in ART treatment adherence. The results of the present study are thus relevant not only for Thailand but also for many other countries with rapidly expanding testing, treatment, and care programs but shortages of financial and human resources. The results underscore the need to incorporate close family members, including parents, more explicitly into programs intended to augment adherence and to facilitate their effectiveness as long-term adherence partners by providing them with adequate information, training and resources. Peers from community based PHA groups can be a particularly valuable and appropriate asset in this regards.

## References

- Beals, KP, RG Wight, CS Aneshensel, DA Murphy & D Miller-Martinez (2006). The role of family caregivers in HIV medication adherence. *AIDS CARE* 18(6): 589-596.
- Burrage, Joe & Alice Demi (2003). Buddy Programs for People Infected With HIV. *Journal of the Association of Nurses in AIDS Care* 14(1): 52-62.
- Chayovan, Napaporn. (1989). Marriage registration among Thai women. *Health and Population Studies Based On the 1987 Thailand Demographic and Health Survey*. Demographic and Health Surveys Further Analysis Series, No. 1. New York: Population Council and Institute for Resource Development.
- Hope, R., & E. Israel. (2007). *The essentials of antiretroviral therapy for health care and program managers*. Pathfinder International, Technical Guidance Series Number 5. Watertown MA: Pathfinder International.
- Knodel, John & Chanpen Saengtienchai. (2004). AIDS & Older Persons: The View from Thailand. In P. Lloyd-Sherlock (ed), *Living longer. Ageing, development & social protection*. London: ZED, 2004, pp. 249-274.
- Knodel, John, Chanpen Saengtienchai & Werasing Sittitrai. (1995). The living arrangements of elderly in Thailand: Views of the populace, *Journal of Cross-Cultural Gerontology* 10: 79-111
- Knodel, John, Jiraporn Kespichayawattana, Suvinee Wiwatwanich & Chanpen Saengtienchai. (2007). *Migration and Inter-generational Solidarity: Evidence from Rural Thailand*. Bangkok: UNFPA.
- Knodel, John & Mark VanLandingham. (2002). The impact of the AIDS epidemic on older persons. *AIDS* 2002, 16, S77-S83.
- Knodel, John & Mark VanLandingham. (2003). Return migration in the context of parental assistance in the AIDS epidemic: The Thai experience. *Social Science & Medicine*, 57, 327-342.
- Knodel, John, Mark VanLandingham, Chanpen Saengtienchai & Wassana Im-em (2001). Older People and AIDS: Quantitative Evidence of the Impact in Thailand, *Social Science & Medicine* 52 (9): 1313-1327.
- Knodel, John & Napaporn Chayovan. (2008). *Population Ageing and the Well-being of Older Persons in Thailand*. Bangkok: UNFPA
- Knodel, John, Susan Watkins & Mark VanLandingham. (2003). AIDS and older persons: An international perspective. *Journal of Acquired Immunodeficiency*, 33, S153-S165.
- Kumphitak, A., S. Kasi-Sedapan, D. Wilson, N. Ford, P. Adpoon, S. Kaetkaew, J. Praemchaiporn, A. Sae-Lim, S. Tapa, S. Teemanka, N. Tienudom, and K. Upakaew. (2004). "Involvement of People Living with HIV/AIDS in Treatment Preparedness in Thailand: Case Study." World Health Organization, Geneva.
- Marino, Patricia, Jane M. Simoni & Louise Bordeaux Silverstein. (2007). Peer Support to Promote Medication Adherence Among People Living with HIV/AIDS: The Benefits to Peers. *Social Work in Health Care*, Vol. 45(1): 67-80
- Mills, Edward, Jean Nachega, David Bangsberg, Sonal Singh, Beth Rachlis, Ping Wu, Kumanan Wilson, Iain Buchan, Christopher Gill, Curtis Cooper (2006). Adherence to HAART: A Systematic Review of Developed and Developing Nation Patient-Reported Barriers and Facilitators. *PLoS Medicine* 3(11): 2039-2064.
- National AIDS Prevention and Alleviation Committee (2008). UNGASS Country Progress Report. Thailand. Reporting period: January 2006 – December 2007.

- Nischal, K. C. Uday Khopkar, D. G. Saple. (2005). Improving adherence to antiretroviral therapy. *Indian Journal of Dermatology Venereology & Leprology*. 71(5): 316-320.
- Ogden, Jessica, Simel Esim & Caren Grown. (2006). Expanding the Care Continuum for HIV/AIDS: Bringing Carers into Focus. *Health Policy and Planning* 21(5) 333-342.
- Revenga, Ana , Mead Over, Emiko Masaki, Wiwat Peerapatanapokin, Julian Gold, Viroj Tangcharoensathien, Sombat Thanprasertsuk. (2006). *The Economics of Effective AIDS Treatment: Evaluating Policy Options for Thailand*. Washington DC: The World Bank
- Russell, Steven, Janet Seeley, Enoch Ezati, Nafuba Wamai, Willy Were and Rebecca Brunnell. 2007. Coming back from the dead; living with HIV as a chronic condition in rural Africa. *Health Policy and Planning* 22:344-347.
- Saengtienchai, Chanpen & John Knodel. (2001). *Parents providing care to adult sons and daughters with HIV/AIDS in Thailand*. Geneva: UNAIDS.
- Sankar, Andrea; Carol Golin, JM Simoni, Mark Luborsky & Cynthia Pearson. (2006). How Qualitative Methods Contribute to Understanding Combination Antiretroviral Therapy Adherence. *JAIDS*. 43(Suppl 1): S54-S68.
- United Nations (2008). *Caregiving in the context of HIV/AIDS*. (EGM/ESOR/2008/BP.4). Geneva: UN
- UNAIDS (2008). *2008 Report on the global AIDS epidemic*. Geneva: UNAIDS.
- UNAIDS/WHO (2008). *Thailand Epidemiological Fact Sheets on HIV and AIDS, 2008 Update*. Geneva: UNAIDS/WHO.
- United Nations Children's Fund (UNICEF). (2006). *Caring for Children affected by HIV and AIDS*. Florence: Innocenti Research Center.
- VanLandingham, Mark, Wassana Im-em, & Chanpen Saengtienchai. (2005). Community reaction to persons with HIV/AIDS and their parents in Thailand. *Journal of Health and Social Behavior* 46 (4):392-410.
- Van Damme, William, Katharina Kober, Guy Kegels. (2008). Scaling-up antiretroviral treatment in Southern African countries with human resource shortage: How will health systems adapt? *Social Science & Medicine* 66 2108-2121
- Ware, Norma, Monique A Wyatt & David R. Bangsberg. (2006). Examining Theoretic Models of Adherence for Validity in Resource-Limited Settings: A Heuristic Approach. *JAIDS* 43(Suppl 1): S18-S22
- Ware Norma, John Idoko, Sylvia Kaaya, Irene Andia Biraro, Monique A. Wyatt, Oche Agbaji, Guerino Chalamilla, David R. Bangsberg. (2009). Explaining Adherence Success in Sub-Saharan Africa: An Ethnographic Study. *PLOS MEDICINE* 6 (1):39-47.
- Williams, Nathalie, John Knodel, Sovan Kiry Kim, Sina Puch & Chanpen Saengtienchai (2008). Overlooked Potential: Older-age Parents in the Era of ART. *AIDS Care* 20(10): 1169-1176.
- World Health Organization (WHO). (2000). *Key elements in HIV/AIDS care and support*. Geneva: World Health Organization.

## Appendix: Self-Administered Questionnaire for ART Recipients

Place: \_\_\_\_\_

### Project: Older-age Parents and AIDS in the ERA of ART: The Case of Thailand

This questionnaire is part of a research study by Chulalongkorn University to determine the role of parents in assisting persons who are receiving ART. **The questionnaire is anonymous and will not have your name associated with it. Completing the questionnaire is completely voluntary.**

1. Please indicate your sex :     male         female
  
2. Please indicate your age: \_\_\_\_\_
  
3. Are your parents still alive?
 

<input type="checkbox"/> both father and mother are alive	<input type="checkbox"/> both father and mother are deceased ( <i>skip to 9</i> )
<input type="checkbox"/> mother alive but father dead	<input type="checkbox"/> father alive but mother dead
  
4. About how old are your parents?
 

Mother	<input type="checkbox"/> under 50	<input type="checkbox"/> 50-59	<input type="checkbox"/> 60-69	<input type="checkbox"/> 70+	<input type="checkbox"/> deceased
Father	<input type="checkbox"/> under 50	<input type="checkbox"/> 50-59	<input type="checkbox"/> 60-69	<input type="checkbox"/> 70+	<input type="checkbox"/> deceased
  
5. Where do your parent(s) currently live?
 

<input type="checkbox"/> together with you	<input type="checkbox"/> next to you
<input type="checkbox"/> in same village/community	<input type="checkbox"/> in different village/community
  
6. Have your parent(s) ever helped you in any of these matters (*you can answer more than one*)
 

<input type="checkbox"/> take you to get medicines	<input type="checkbox"/> remind you to get medicines	<input type="checkbox"/> prepare medicines
<input type="checkbox"/> never helped in these matters		
  
7. Do your parent(s) know that you are taking ART medicines?
 

<input type="checkbox"/> yes	<input type="checkbox"/> no
------------------------------	-----------------------------
  
8. Do your parent(s) help remind you to take your medicines
 

<input type="checkbox"/> every day or almost every day	<input type="checkbox"/> not every day but often
<input type="checkbox"/> not often but sometimes	<input type="checkbox"/> never <input type="checkbox"/> used to but not now
  
9. Do any of the following persons help remind you to take your medicines? (*check everyone who helps*)
 

<input type="checkbox"/> spouse/partner	<input type="checkbox"/> children	<input type="checkbox"/> sibling	<input type="checkbox"/> relative
<input type="checkbox"/> friend	<input type="checkbox"/> PWA group	<input type="checkbox"/> other (if yes who? _____)	
  
10. Do you currently live with any of the following persons? (*check everyone who lives with you*)
 

<input type="checkbox"/> spouse/partner	<input type="checkbox"/> children	<input type="checkbox"/> sibling	
<input type="checkbox"/> relative	<input type="checkbox"/> friend	<input type="checkbox"/> other (if yes who? _____)	<input type="checkbox"/> live alone
  
11. What type of insurance that covers your ART medicines?
 

<input type="checkbox"/> universal coverage(gold card)	<input type="checkbox"/> social security	<input type="checkbox"/> civil service
<input type="checkbox"/> other (specify _____)		

**Thank you for your cooperation.**