



Research Report

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ABSTRACT

Ensuring treatment adherence is critical for the success of ART programs in developing countries. Enlisting NGOs or PLHA group members as treatment supporters is one common strategy. Less attention is given to family members and especially older-age parents. Yet ART patients often live with other family members who are highly motivated to ensure treatment success. This study examines the role of family members and especially parents in assisting adherence in Cambodia and Thailand among adult ART patients. Most have a living parent and many live with or near a parent. Family members including parents commonly remind patients take medications, particularly if coresident in the same household. Parents also remind patients to get resupplies and accompany them to appointments. Some contrasts between Cambodia and Thailand emerged. Fewer Cambodian than Thai patients had a living parent. However, among those who did, equal shares lived with parents. Cambodian parents more commonly reminded patients to take medications and get resupplies and accompanied them when doing so. In both countries correct knowledge of ART among parents was associated with the amount of advice from program personnel. The results underscore both the need to more explicitly incorporate close family members, including parents, into efforts to promote adherence and need for PLHA peers and home based care teams to provide them with adequate information, training and resources to increase their effectiveness.

INTRODUCTION

Just a few years ago in most low- and middle-income countries the onset of AIDS related illnesses led to a rapid decline in health followed by certain death. Studies in a variety of settings indicated that family members of HIV infected adults, and particularly parents who were typically in advanced ages, made substantial contributions to how society coped with the epidemic by providing personal care, emotional support and material assistance to those who were infected and by raising orphaned grandchildren left behind (e.g. Boon et al. 2010; Chazan 2008; Knodel and VanLandingham 2002; Knodel, Watkins and VanLandingham 2003; Ogden, Esim & Grown 2004; Reddy et al. 2009; Ssengonzi 2009; Williams, Knodel & Lam 2010). Yet older-age parents have been virtually absent in the discourse of the international and national agencies charged with dealing with the epidemic except for mention of their raising AIDS orphans.

With the widening availability of antiretroviral therapy (ART), increasing numbers of persons living with HIV/AIDS (PLHA) receive effective treatment and regain reasonable health. Some even avoid serious illness if the medications are started before opportunistic infections occur. As a result, many of the adverse effects of the epidemic on family members that were prevalent prior to the expansion of ART have likely declined and are at least significantly delayed. At the same time, effective use of ART requires sustained adherence to drug regimens, attention to diet and exercise, and coping with potentially severe side effects. This presents a major challenge to health systems, especially in resource limited countries where demands on health personnel are often already excessive (UNESCAP 2009a; WHO Regional Office for South-East Asia 2009).

Augmenting adherence through treatment supporters, sometimes labeled ‘buddy programs’, drawn from PLHA support groups is most common strategy to deal with this challenge (Burrage & Demi 2003; Hope & Israel 2007; Marino et al. 2007; UN 2008). While there is some recognition that family members have a role to play, their importance receives less emphasis and older generation members are virtually never mentioned. Yet widespread access to ART creates new opportunities for family members, including the older-age parents of adults or grandparents of young orphaned children under treatment, to provide such assistance. Indeed, 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 parents, are particularly appropriate.

The present study assesses the role of parents and other family members in helping with treatment adherence among adult ART recipients in Cambodia and Thailand. The findings and recommendations stemming from this research are likely relevant for many other settings where family members, including those of more advanced age, live with or near ART patients and are often routinely involved in their daily lives.

BACKGROUND

Cambodia and Thailand provide interesting settings to compare the contribution of family members in dealing with the AIDS epidemic. While both countries share value systems that are strongly grounded in Theravada Buddhism, they differ starkly in terms of economic and social development. Within Southeast Asia, Cambodia scores lowest on the UN Human Development index while Thailand has one of the highest scores (UNESCAP 2009b). Thailand is considered a middle income country with a per capita GNI (Gross National Income measured in purchasing power parity) more than four times that of Cambodia (UNFPA 2009). Indeed, Cambodia is among the poorest countries in all of Asia with per capita GNI similar to many in sub-Saharan Africa. Moreover Cambodia suffered a traumatic recent history of severe political unrest and violence losing a very substantial portion of its population during civil war and the disastrous rule of the Khmer Rouge in the 1970s. While Thailand experienced some political instability, civil war and widespread political violence has been absent during the last half century.

Earlier research in both countries documented that prior to the widespread provision of ART, a substantial majority of adults who died of HIV/AIDS had one or both parents surviving at the time and that in most such cases, PLHA lived with or nearby a parent and received parental care and financial support (Knodel et al. 2001 and 2007). The substantial involvement of parents was fostered by the fact that many adult children normally remained with or near parents and many who migrated away but became infected returned when they became ill (Knodel and VanLandingham 2003).

In recent years in both countries, the context of the epidemic has changed substantially. Although HIV prevalence in Thailand and Cambodia have been among the highest experienced in Southeast Asia, fuelled largely by widespread commercial sex, both countries have been successful in sharply reducing incidence through vigorous efforts including promoting 100% condom use in commercial sex establishments (Ainsworth, Breyer & Soucat 2003; Buehler et al 2006). Both countries also offer free ART at government expense and have been among the most successful in the developing world in moving towards universal access. As a result, substantial majorities of Cambodians and Thais in need of treatment are now receiving it (UNESCAP 2009a).ⁱ

In both Cambodia and Thailand, efforts to augment treatment adherence are being made within a 'continuum of care' framework. So far, such efforts in Thailand focus mainly on the role of PLHA groups and peer assistance (Lyttleton, Beesey & Sitthikriengkrai 2007; National AIDS Prevention and Alleviation Committee 2008; Revenga et al. 2006). A project was initiated in 2002 to encourage adherence through PLHA peer support groups typically affiliated with hospitals. Designated group members do counseling and make home visits during which their responsibilities include providing information to family members about the importance of adherence (Kumphitak et al, 2004). Expansion of the

program is underway and by September 2009 incorporated over 350 groups in approximately half of the hospitals with an ART program. In addition, some PLHA groups not formally associated with the program also provide assistance with treatment adherenceⁱⁱ. It is notable that for the first time the *10th National AIDS Plan (2007-2011)* includes older people affected by HIV/AIDS as a specific target group for interventions (Orbach 2007). Overall, the Thai HIV program is financed largely through domestic funds (WHO Regional Office for South-East Asia 2009).

The public health system in Cambodia is considerably weaker than in Thailand but HIV/AIDS is addressed through an aggressive and effective vertical program (Buehler et al. 2006; WHO 2006). Within a 'continuum of care' framework, the government has partnered with a collation of NGOs which are largely responsible for operating home-based care teams that visit ART and OI treatment recipients. According to a recent national program report, about 73% of health centers are associated with home based care teams and about half of ART recipients receive home based care support (Cambodia, NCHADS 2009). Thus it is likely that at present, home based care is more extensive in Cambodia than Thailand. However, the revised National AIDS plan makes no mention of the role or needs of older persons in relation to the epidemic other than referring to grandparents caring for orphaned and vulnerable children (Cambodia, National AIDS Authority 2007). Also, unlike Thailand, financing of the HIV program including the NGO component is heavily dependent on external funds (UNESCAP 2009a).

METHODS

Data for the present study were collected using two approaches.ⁱⁱⁱ The first involved surveys of 340 adult ART recipients in Cambodia during May 2008 and 912 recipients in Thailand between September 2008 and February 2009 using virtually identical one-page anonymous questionnaires. Recipients were asked about their living arrangements, whether they had living parents, and treatment adherence assistance from family members. More detail was asked about the role of parents than of others since the focus was on the role of older persons. Most of the analysis presented below is based on this source.

In Thailand, the ART recipient survey was self administered. Nurses asked patients coming for resupply to complete the questionnaires. Sample sites consisted of at 2 hospitals in Bangkok and 16 hospitals in 5 provinces around the country including at least one province in each of the four major regions. In each of the provinces included the provincial hospital and 2 district hospitals at differing distances from provincial capital were selected.^{iv} The sample numbers for each of the provinces and for Bangkok are approximately the same. Nurses at each site unanimously reported that almost everyone

asked was willing to comply. The high response rate likely reflects the short questionnaire length, the lack of sensitive questions, and generally good relations between nurses and patients in the program. Although the sample was purposive, it closely resembles the national pool of adult ART recipients in gender composition and in the proportions using the three alternative insurance schemes through which ART can be obtained from a government hospital (Knodel et al. 2010).

In Cambodia, the ART recipient survey took place in six communes of the north-western province of Banteay Meanchey. Questionnaires were administered to 340 adult ART recipients mainly by home based care team members who worked under NGOs in the sample communes after receiving instructions from ADI staff. Given the limitation to six communes in just one province, the Cambodian ART recipient sample is less likely to be representative of the broader population of adults on ART than the Thai sample. It included, however, both rural and urban communes and we have no reason to suspect that the chosen province is unusual with respect to the issues being investigated. Women outnumber men in the sample as in the national pool of adult ART patients although the gender imbalance is somewhat more pronounced in the sample.^v Comparisons between Thai and Cambodian results and associated measures of statistical significance of differences should be considered as only suggestive given the differences in the sampling and that for both surveys sample site selection was purposive.

The second data collection approach involved detailed face-to-face interviews with convenience samples of 108 older persons in each country who were involved with an ART recipient. Although the interviews covered many of the same topics in both countries, the questionnaires differed considerably. In the case of Thailand, interviews took place between September 2008 and February 2009 and involved parents of an adult recipient including 82 in which the parents and recipient coresided.^{vi} In Cambodia, interviews took place in May 2008 and involved 80 with parents of an ART recipient, 60 of whom coresided with the recipient, and 28 with older persons who lived in the same household as someone on ART other than their own child (e.g. a child-in-law or a grandchild).^{vii} In Thailand, respondents in sites in all four regions of the country were identified and contacted through PLHA support groups and interviews were conducted by recent graduate nurses and their professors (who were principal investigators in the research project). In Cambodia, respondents were identified through home based care teams and interviews were conducted by participants in a research training program for staff NGO. In the present study, data from the older person interviews is limited to examining the association between ART-related knowledge and contact with persons associated with the ART program.

RESULTS

Sample characteristics

As Table 1 shows, the ART recipient surveys indicate that in both Cambodia and Thailand most recipients have a living parent although there is considerable difference between the two samples with over 80% of Thai recipients reporting a living parent compared to just over 60% of Cambodian recipients. The lower percentage in Cambodia likely reflects the overall poorer health conditions and consequent higher mortality than in Thailand as well as the legacy of the Khmer Rouge period when many adults today were children and lost parents, particularly fathers, to the harsh conditions and violence of the time. Still, even in Cambodia, over half of adult ART recipients have a living mother and in Thailand almost three fourths do. This is important in relation to parental assistance to ART recipients given that previous research in both countries shows that mothers played a more active role in caregiving of HIV infected adult children than fathers (Knodel et al. 2001 and 2007).

Also shown in Table 1, most parents of adult ART recipients are at advanced ages with few under age 50. Nevertheless the Thai parents are notably older than their Cambodian counterparts, likely reflecting the later ages of marriage and childbearing that prevailed in Thailand compared to Cambodia for a number of decades. Less difference between the two samples is evident in the age distribution of the recipients themselves although the Cambodian sample are modestly younger on average and somewhat more concentrated in younger adult ages than the Thai sample. Somewhat more striking are the differences in the gender distributions of recipients, with women representing almost 60% of the Cambodian sample while the Thailand sample is divided equally between the sexes.

As noted in the introduction, assistance with treatment adherence on a routine basis is far more practical for persons who live with or very nearby the person on ART. Thus living arrangements of ART recipients have considerable bearing on who is potentially available for assistance. As Table 1 indicates, few recipients live alone although solitary living is modestly more common among the Thai than the Cambodian sample.^{viii} Likewise, living with a non-relative is uncommon in both samples. At the same time, there are substantial differences between the two samples with respect to the composition of relatives with whom recipients live. Almost two thirds of Cambodian compared to less than one third of Thai recipients reported living with one or more of their children, likely reflecting the much higher fertility in Cambodia than in Thailand over recent decades. Half or more of Cambodian and Thai recipients report living with a spouse/partner, although the proportion is higher for Cambodians, likely reflecting the younger prevailing age of marriage in Cambodia.^{ix}

Table 1. Characteristics of antiretroviral therapy patients and age distribution of their parents

	Cambodia	Thailand	Significance level ^(a)
Number of cases			
ART recipients	340	912	n.a.
Parents with reported age	298	1145	n.a.
Living status of parents			
% with any living parent	60.6	82.8	***
% with a living mother	55.9	73.2	***
% with a living father	31.8	60.0	***
% with both parents living	27.1	42.3	***
Age of parents (% distribution)			***
Under 50	4.6	7.0	--
50-59	38.6	31.5	--
60-69	40.4	36.7	--
70+	16.5	24.8	--
Gender of recipient (% distribution)			*
Male	41.0	49.1	--
Female	59.0	50.9	--
Age of recipients (% distribution)			n.s.
18-34	37.1	31.5	--
35-44	43.5	48.8	--
45+	19.4	19.6	--
Mean age of recipients	37.7	38.5	n.s.
Living arrangements			
% living alone	2.9	7.4	**
% living with parent	24.8	33.3	**
% living with spouse/partner	57.1	51.6	n.s.
% living with child(ren)	64.1	31.7	***
% living with sibling	19.1	14.0	*
% living with non-relative	5.9	4.4	n.s.
Location of parents among cases with a living parent (% distribution)			n.s.
In same household	41.8	40.3	--
In same locality, different household	28.1	22.9	--
Elsewhere	30.1	36.7	--

Source: ART recipient surveys

(a) Statistical significance is measured either by Chi square or t-tests and is only suggestive: *=.05 level; **=.01 level; ***=.001 level.

Cambodian ART recipients are also slightly more likely than Thai recipients to live with a sibling although in both samples only modest minorities do so. In contrast, living with a parent is substantially more common for Thai than Cambodian recipients with a third in the Thai sample compared to only a fourth in the Cambodian sample doing so. The difference is entirely attributable to the higher proportion of Thai than Cambodian recipients who have a surviving parent. Among those who have at least one living parent, two fifths of both samples report coresidence with a parent. Moreover, substantial majorities (70% of Cambodian and 63% of Thai) recipients who have a living parent report living at least in the same locality as their parents.

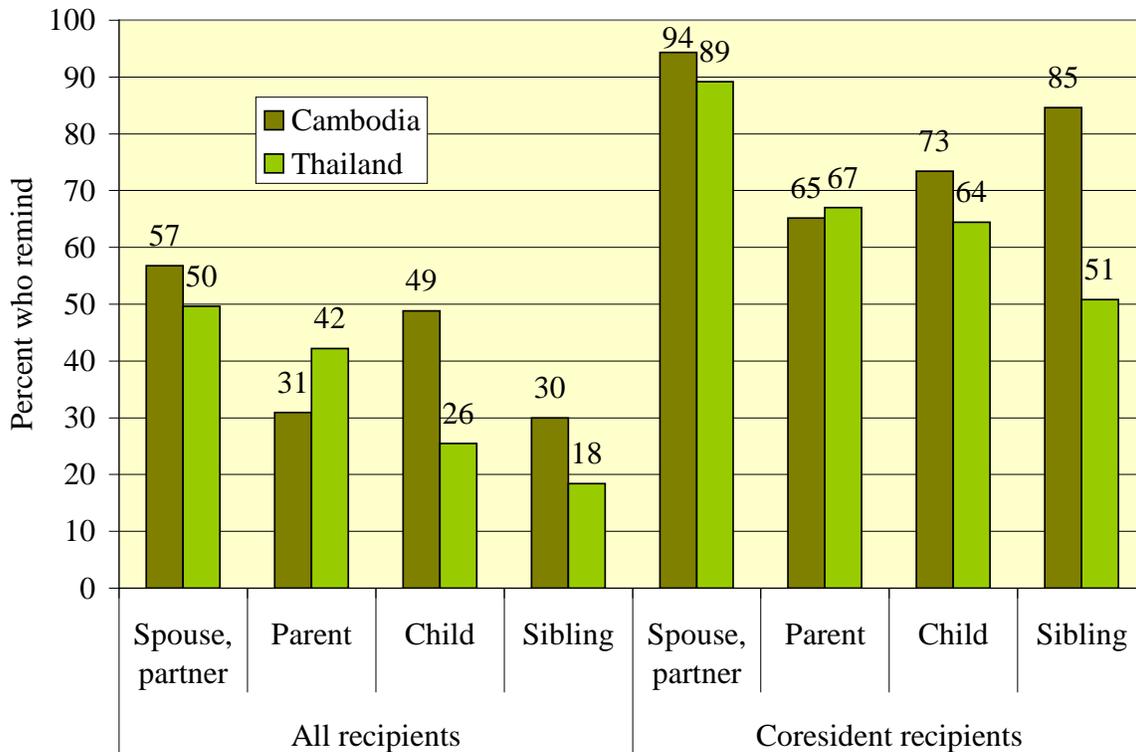
Treatment assistance

ART recipients were asked to indicate if different types of persons helped remind them to take their medications. Since coresidence greatly facilitates the ability to do so, results in Figure 1 are shown both for the total samples and conditioned on living in the same household with the particular type of person under consideration. Results for all recipients are intended to reflect the potential importance of specific types of family members for the general population of adult ART patients at large and thus are not conditioned on having a family member of the specific type shown. Note that the question for persons other than parents did not ask about the frequency of reminding. Hence results in Figure 1 refer to reminding even if done only occasionally.^x

Among all recipients, the most common person to help remind them to take their medications in both samples is a spouse or partner with half of the Thai sample and 57% of the Cambodian sample indicating this to be the case. Thai recipients report parents as second most common but for Cambodian recipients, parents trail behind children. The fact that, among all recipients, a parent is far more likely to remind than a child among Thais while the reverse is true for among Cambodians likely is a function of differences between the two samples in the proportions who have a living parent and who have a child. When results are conditioned on coresiding in the same household with the specific types of persons shown, large proportions of coresident family members regardless of relationship are said to help remind the ART recipient to take medications. This suggests substantial concern for the recipient's well-being among family members. Moreover, differences between Cambodia and Thailand become far more modest except with respect to the role of siblings.

Table 2 focuses on parents based on recipient survey questionnaire items that were specific to their role. Results are limited to ART recipients with a living parent and presented for all such recipients as well separately for those coresiding with a parent. Most recipients report that their parents know that they are on ART and this is especially so for those who coreside with parents. At the same time, parental awareness is noticeably higher in the Cambodian than Thai samples with over 90 percent of Cambodian recipients with a living parent compared to three-fourths of Thai recipients reporting that their parents know they are on ART.

Figure 1. Percentage who currently remind ART recipient to take medications by relationship to recipient



Source: ART recipient surveys

Notes: For all ART recipients, differences between Cambodia and Thailand are statistically significant at the .05 level for spouse/partner and at the .001 level for all other relationships; for coresident recipients, differences between Cambodia and Thailand are statistically significant at the .001 level for siblings, at the .05 level for spouse/partner and children, and not significant for parents. Statistical significance is measured by t-tests and is only suggestive.

(a) refers to the subsets of recipients who live in the same household with a persons of each type of designated relationship.

Results in Table 2 also indicate that parents commonly assist with treatment adherence assistance. Less than two fifths of ART recipients with living parents in both samples report that a parent never reminded them to take their medications although 10% reported that parents used to remind them but no longer do so. This may represent cases where the recipient no longer needs reminding. Among those who coreside with a parent less than a fourth in both samples indicate parents never reminded them. Differences in the frequency that parents remind, however, are evident with Cambodian parents being more likely to remind frequently than Thai parents. Still even among Thai ART recipients, one-fourth with a living parent report that parents remind them either daily or often to take their medications and another fourth that parents remind them sometimes.

Table 2. Awareness of treatment and treatment assistance by a parent to all ART recipients and to recipients who are coresident with a parent

	All recipients with a living parent			Recipients coresident with a parent		
	Cambodia	Thailand	Significance level ^(a)	Cambodia	Thailand	Significance level ^(a)
N of cases ^(a)	206	755		82	301	
% whose parents are aware PLHA is on ART	91.6	72.5	***	98.8	86.3	***
How often parent reminds PLHA to take medicines (% distribution)			**			***
daily/almost daily	23.8	14.8	--	47.6	24.7	--
often but not daily	10.7	10.4	--	9.8	12.3	--
sometimes	16.5	25.9	--	13.4	30.7	--
used to but not now	10.2	10.2	--	6.1	8.3	--
never	38.8	38.7	--	23.2	24.0	--
total	100	100	--	100	100	--
% receiving other assistance from a parent						
Reminded to get medicines	61.7	44.4	*	80.5	57.5	***
Taken to get medicines	25.7	18.8	***	42.7	23.6	***
Prepared medicines	16.5	7.2	***	31.7	10.0	***
Any of the 3 tasks above	68.9	54.2	***	91.5	70.8	***
Parental treatment assistance score ^(b)	2.00	1.58	***	2.89	2.04	***

Source: ART recipient surveys

(a) Statistical significance is measured either by Chi square or t-tests and is only suggestive: *=.05 level; **=.01 level; ***=.001 level.

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

Besides remembering to take medicines on time, adequate adherence also involves regularly obtaining resupplies and having the medications ready to take. To determine parental assistance in these matters, ART recipients were asked if their parents ever reminded them to go for resupply, had ever taken or accompanied them when going for resupply, and if they had helped prepare the medication to take. The proportions of Cambodian ART recipients with a living parent who reported parental assistance in these matters is noticeably higher than for Thai recipients. Still over half (54%) of Thai recipients with a living parent and over 70% of those coresident with a 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.

Table 2 also provides an overall 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 signifying greater parental assistance. In both samples, living with a parent is clearly associated with higher scores. In addition, parental treatment assistance scores are noticeably higher for the Cambodian than the Thai sample both for all recipients with a living parent and for those who coreside with a parent.

Knowledge of ART

An important prerequisite for parents and other family members to effectively assist ART treatment adherence is correct acknowledgment of the requirements. Both the Cambodian and Thai AIDS programs encompass several components through which family members, including older age parents, can obtain useful information to improve their ability to effectively care for PLHA when ill or assist with treatment support. These include contact with health professionals at service sites as well as home visits by personnel associated with the AIDS program including, especially in Thailand, PLHA support group members. Also, PLHA support groups typically conduct regular meetings during which useful information is exchanged and in some cases family members attend.

In the present study interest focuses on the association of knowledge and the extent to which the older persons had contact with or received advice from the HIV/AIDS care and treatment programs. Information on knowledge of ART and receipt of advice from program sources was collected in both countries in interviews with the older persons who were involved with an ART recipient. Although the particular series of questions differed, summary scores of knowledge and sources of advice can be computed for each sample of older persons. These in turn can be used to examine the association between knowledge and advice within each sample and the results of these separate analyses can then be compared.^{xi}

A knowledge score for older persons interviewed in Cambodia was calculated as the number of correct responses to 8 questions concerning whether ART was available free of charge, how often ART medications needed to be taken, how often resupply was needed and awareness of five specific requirements of the ART program. For the Thai sample of parents of ART recipients, a knowledge score was based on five questions asking how often ART medications needed to be taken, if it is important to take ART medications at the same time every day, how often resupply was needed, where to go for resupply, and awareness of tests for CD4 counts. One point is given for each correct or plausible answer to the first four questions and an additional point for awareness of CD4 tests. One point was subtracted for each question a respondent could not the answer.

In the Cambodian study, the extent of advice received was measured by the number of six possible sources from which respondents indicated having received advice on how ART medicines should be taken. In the Thai study, parents of ART recipients were asked if they received advice on three different matters: caring for someone with HIV/AIDS before their adult child was on ART, caring for someone on ART, and general information on ART. The parents interviewed were also asked if they had ever attended a PLHA support group meeting (where presumably information on ART would be provided). The number of positive responses to these four items serves as a summary measure of the types of advice received.

Since persons with higher levels of education may not only have better knowledge of ART but also be more prone to seek advice, it is useful to control for educational attainment when examining the association between advice received and ART knowledge. Table 3 shows ART knowledge in relation both to the educational level of the respondent and the amount of advice received concerning HIV/AIDS and ART. Mean knowledge scores are presented unadjusted and after statistical adjustment to control for the other covariate. Unadjusted results indicate that in both Cambodia and Thailand there is a strong association between the extent of advice received and ART knowledge. Education shows a clear association with knowledge among Cambodian older persons but not for the Thai sample. Adjusting for education, however, only slightly weakens the association between the number of sources of advice and ART knowledge in the Cambodian sample and has virtually no effect on the association between the number of types of advice and ART knowledge in the Thai sample. Thus it appears that receiving advice from program sources considerably improves older persons knowledge.

It is interesting to note that in both the Cambodian and Thai samples of older persons, those with better ART knowledge were also more likely to report that they reminded their adult child or relative to take medications (results not shown in table). For example, among Cambodian older persons, 100% of those whose score was above the median said that they or their spouse reminded the ART recipient to take medications compared to only 47% of those whose knowledge score was below the median. Among Thai older parents interviewed, 76% of those whose knowledge score was above the median compared to 60% whose knowledge score was below the median indicated they had ever reminded their adult child to take medications. This association of course does not necessarily imply causality. Respondents who are more motivated and active in encouraging their adult child or relative to adhere may also be more motivated to learn about ART requirements. Thus rather than knowledge leading to a greater tendency to help remind taking medications, the causation could run in the reverse direction. Still, it seems plausible that better informed respondents are more effective than those who know less about ART in providing treatment support and that causality runs in both directions.

Table 3. ART knowledge score by literacy, education, whether parent was advised regarding ART or post-ART care, whether home visitor explained ART, and whether the parent, Thailand

	Number of cases	Knowledge score ^(a)	
		Unadjusted	Adjusted ^(b)
<i>Cambodia</i>			
Education			
None	49	3.86	4.01
1-5 years	36	4.75	4.77
6+ years	23	5.61	5.25
Significance level	n.a.	**	*
Number of sources of advice ^(b)			
None	32	3.19	3.33
1-2	56	4.89	4.91
3-4	20	5.65	5.38
Significance level	n.a.	***	***
<i>Thailand</i>			
Education			
0-3 years	27	2.70	2.83
4 or more years	81	2.54	2.50
Significance level	n.a.	n.s.	n.s.
Number of types of advice			
None	29	1.07	1.04
1-2	38	2.58	2.61
3-4	41	3.66	3.65
Significance level	n.a.	***	***

Source: Older person interviews

Notes: See text for definitions of knowledge score and measures of advice.

(a) Determination of knowledge scores is country specific and thus scores are not comparable within but not between countries..

(b) Statistically adjusted by multiple classification analysis (MCA) a form of dummy variable multiple regression.

DISCUSSION AND CONCLUSIONS

A major challenge that programs in developing countries aiming to provide universal ART coverage face is the need to ensure high levels treatment adherence necessary to sustain the health benefits for the patients and to minimize drug resistance associated with treatment failure. Enlisting peers from PLHA support groups as treatment partners, such as in Thailand, is a particularly common adherence augmentation strategy. A somewhat different model is followed in Cambodia where NGOs, in coordination with

the Government HIV/AIDS program, take responsibility for home based care teams and together with PLHA support groups promote adherence. While likely cost-effective, such programs still entail administrative expenses and payments for those involved. This can be a concern in resource-limited settings where funding is tight, especially as ART programs expand. Moreover, in countries such as Cambodia, where funding is primarily dependent on external sources, sustaining these activities is vulnerable to changes in priorities and financial resources of donor sources (Mills et al. 2010).

Although family members are sometimes mentioned in the context of treatment support, they receive far less attention than PLHA peers in the discourse of international agencies concerned with the epidemic or in most national program plans. Moreover, when they are mentioned, distinction is rarely made in terms of relationships to the ART patient. In particular, older generation members such as parents are almost never specifically cited. Their neglect may reflect assumptions that older persons, who in poorer countries typically have low levels of formal education, are incapable of sufficiently understanding ART to provide useful assistance.

The present study examined evidence from adult ART recipients and older persons with a son or daughter or a coresident relative on ART in Cambodia and Thailand. It has several weaknesses including the non-probability nature of the samples, the limited amount of information collected from the recipients, and the small sample size of older persons interviewed. Nevertheless the results provide clear evidence that most adult ART patients have a living parent and many live with or in the same locality as a parent. The results also document that family members, including parents, commonly help ART patients to remember to take their medications, particularly when they live in the same household. Parents also assist in other ways, including reminding their adult child to go for resupplies of medications and bringing them to their appointments. An important issue that is not addressed but which would be an appropriate topic for future research is the degree to which actions by parents/family members actually affect adherence.

Some contrasts between the Cambodia and Thailand results emerged. Substantially fewer adult ART recipients had a living parent in the Cambodian than the Thai sample. Although among recipients with a living parent, equal shares coresided with parents in both samples, more resided outside the parent's local area in the Thai than in the Cambodian sample. Cambodian recipients with a living parent were also more likely than Thai recipients to report that their parents know they are on ART, that parents reminded them to take medications and to get resupplies, and that parents accompanied them when doing so.

Given the non-probability nature of the samples, these differences can only be considered as suggestive of general patterns within the two countries. Still, other evidence supports their plausibility. Nationally representative surveys document that adult Cambodians in

general are less likely to have a living parent than adult Thais, undoubtedly reflecting higher mortality in Cambodia and the legacy of the deadly Khmer Rouge period (Knodel 2009). Broadly representative surveys also indicate that adult children of older age parents are more likely to live away in Thailand than Cambodia, likely reflecting more widespread employment opportunities in the more developed modern sector of the Thai economy (Zimmer et al. 2008). Finally, as noted in the background section above, home based care teams have more complete coverage in Cambodia than Thailand, a situation that could contribute to making family members including parents aware that the recipient is undergoing treatment and encouraging them to assist with adherence.^{xii}

The relative lack of attention given to family members, including older-age parents, in augmenting adherence is unfortunate. Parents and other family members often live with or near ART patients and have deep emotional reasons for wanting the patient to achieve and maintain restored health. 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. They are thus ideally positioned to assist with treatment adherence over long periods of time. In addition, they neither need nor expect financial compensation for their assistance. The only costs involved would be ones associated with providing sufficient information and training to enable them to carry out such assistance effectively. These advantages hold not only in Cambodia and Thailand but in many other settings as well.

The interviews with older persons in both Cambodia and Thailand indicate that basic knowledge of the treatment and its requirements is strongly associated with the amount of advice they received related to ART and HIV/AIDS caregiving. It is unrealistic to expect PLHA peers or home based care teams from NGOs to assist on the same frequent and continuous basis that family members could. However, they can play an important role in providing the information and training needed to facilitate family members' effectiveness in providing treatment adherence support. They can also provide critical supplemental support including occasional monitoring of the family's situation and acting as intermediaries between the family and the health system. Results from both Cambodia and Thailand underscore the need to incorporate close family members, including parents, more explicitly into programs intended to augment adherence. At the same time they point to the important role that PLHA peers and home based care teams can play in facilitating their effectiveness by providing them with adequate information, training and resources.

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Endnotes

- ⁱ By 2007 around 80% of adults and children with advanced HIV infection in both Cambodia and Thailand were estimated to have received ART (According to UNESCAP 2009a).
- ⁱⁱ Information provided by ACCESS.
- ⁱⁱⁱ Data collection in Thailand was under the auspices of the Chulalongkorn University Faculty of Nursing and in Cambodia under the auspices of the Analyzing Development Issues (ADI) project of the Cooperation Committee for Cambodia (CCC).
- ^{iv} In one province three district hospitals were included.
- ^v Females represent 59% in the sample. According to program statistics 52% of ART recipients age 15+ nationally and 54 % in Banteay Meanchey province were female at the end of 2009 (Cambodia, NCHADS 2010).
- ^{vi} Although no age limit was set for respondents, all but one was over age 50.
- ^{vii} The Cambodian interviews were purposively limited to persons age 50 or older.
- ^{viii} This difference is in part due to the fact that the Thai sample includes recipients residing in provincial capitals and Bangkok where living alone is considerably higher than in rural areas. Among Thai recipients at community hospitals, only 5.4% lived alone.
- ^{ix} Although the questionnaires did not distinguish between spouses and partners, very likely the vast majority who report living with a spouse or partner are referring to living with someone considered to be their spouse even if the marriage is not registered.
- ^x Response categories for the question about the frequency that parents reminded included “used to but not now” and “never reminded”. For Figure 1, these categories are treated as not currently reminding and other responses regardless of frequency as currently reminding.
- ^{xi} The purposive nature of the samples and the means of recruitment for interview likely resulted in samples of older persons in both countries that are skewed towards respondents who are more involved with their child or relative on ART than would be otherwise be the case. However, this should not necessarily affect the association between knowledge and amount of advice received.
- ^{xii} The interviews with older persons in the two sample sites provides evidence consistent with a more active home based care program in Cambodia than Thailand. According to these interviews, 75% in Cambodia said that the ART recipient was visited by a home care team and of those visited almost half said visits were at least monthly. Among Thai parents of ART recipients, 64% said that the recipient was ever visited and only 15% of those visited received regular visits.



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