

Older-age parents and the AIDS epidemic in Thailand



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impacts in the era
of antiretroviral therapy





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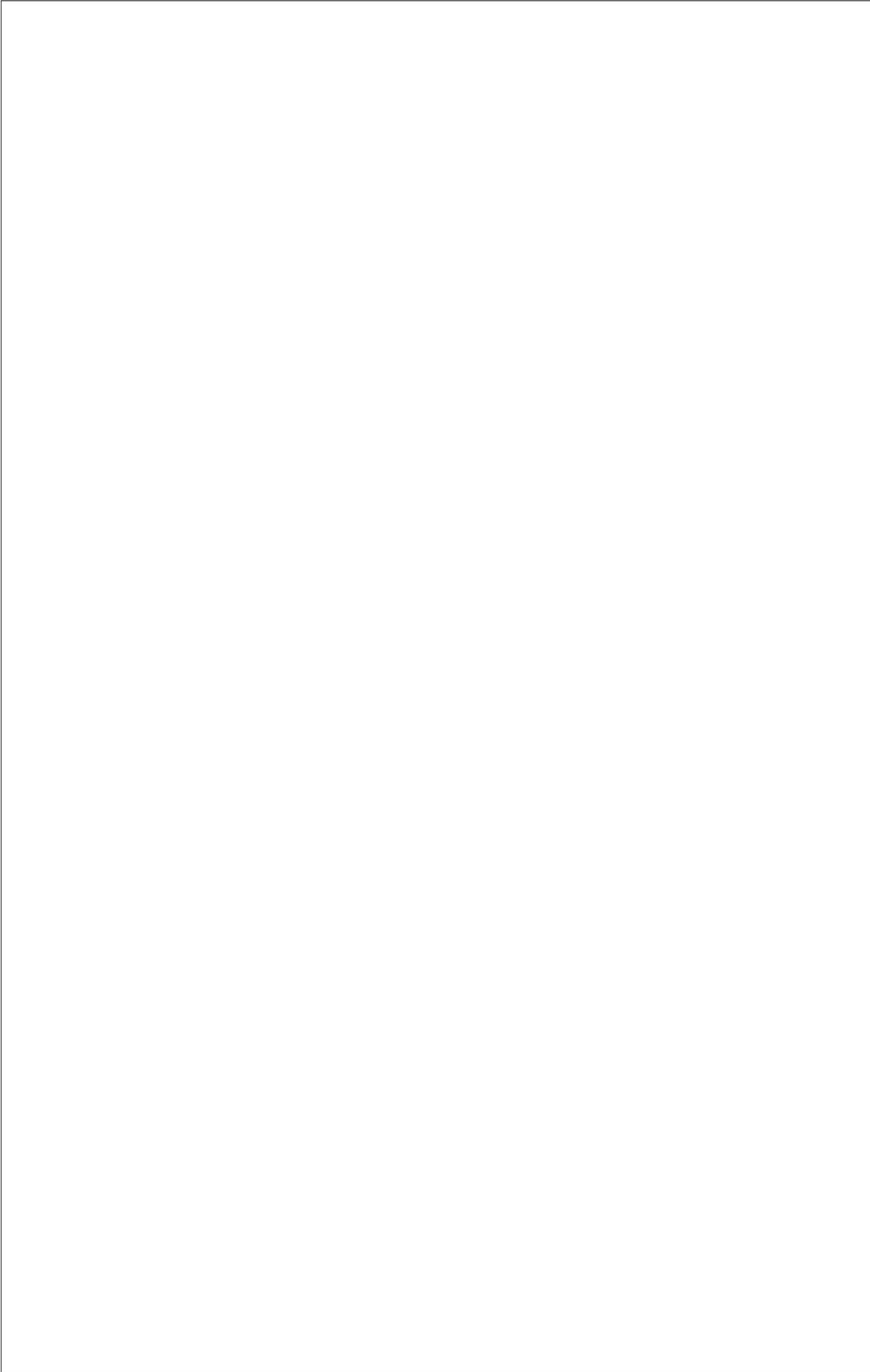
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PREFACE

As the number of older persons is set to double at an unprecedented rate in the ESCAP region over the next few decades, it is becoming increasingly important to engage and address the issue of older persons in development. In view of the impact of ageing in Asia and the Pacific, ESCAP has been working actively to build the capacity of its member States in their ageing readiness. At the 2002 Second World Assembly on Ageing, Governments came together to adopt the Madrid International Plan of Action on Ageing, 2002, which for the first time recognized the contribution and role of older persons in international development. ESCAP provided the forum to scale this framework down to the regional level through the Shanghai Implementation Strategy for the Madrid International Plan of Action on Ageing and Macao Plan of Action for Asia and the Pacific, which was adopted in 2003. One area that these international and regional frameworks of action on ageing have highlighted is the specific need for action to promote support systems for elderly caregivers of persons living with HIV/AIDS.

The purpose of this publication is to disseminate the findings of the report on “Older-age parents and the AIDS epidemic in Thailand: Changing impacts in the era of Antiretroviral Therapy” to assist policymakers addressing similar contextual environments to further understand the epidemic and its impact on elderly caregivers. The report represents one of the few research works on the impact of HIV and AIDS on the lives of persons living with HIV/AIDS and their families in the region. It serves to fill the gap in the dearth of research on the implications of the AIDS epidemic on older aged parents, in particular in the context of the increasing availability of antiretroviral therapy.

The Social Development Division of ESCAP has produced other publications to assist policymakers and further knowledge in the area of HIV/AIDS, ageing and related issues (for further information, please visit the ESCAP website <http://www.unescap.org>). This report helps to shed further understanding of the epidemic, the role of older parents in providing support for persons living with HIV/AIDS and intervening factors of this support. The findings will thus be of interest to policymakers, gerontologists and researchers working on issues of elderly caregivers and of HIV/AIDS in the region and beyond.



EXECUTIVE SUMMARY

Background and report objectives

Almost three decades into the worldwide HIV/AIDS epidemic, older persons remain marginal in the discourse of the international and national agencies charged with dealing with AIDS. Persons age 50 and older constitute a modest but growing share of the HIV worldwide caseload. Since most adults living with HIV/AIDS have one or both parents surviving, far greater numbers of older persons are affected through the illness and death of their adult sons and daughters.

Previous research on the impact of the AIDS epidemic on older persons has been quite limited. Nevertheless, the results that have emerged, including from Thailand, make clear that many experienced a range of adverse emotional, economic, and social consequences. Yet their needs have been largely ignored by programmes intended to mitigate the epidemic's impact. At the same time, older persons have contributed substantially to how societies cope with the epidemic, especially by providing personal care, emotional support and material assistance to their infected adult sons and daughters and foster care to their orphaned grandchildren. In recent years, access to antiretroviral therapy (ART) has been increasing rapidly in many low- and middle-income countries. As a result, HIV/AIDS is becoming a chronic but manageable condition rather than one leading to debilitating illness and certain near-term death. This has important implications for parents and other family members of persons living with HIV/AIDS (PLHA) and the contributions they make.

This report examines the situation in Thailand and focuses primarily on parents of adults on ART but also includes some comparisons with other family members. Thailand provides a particularly appropriate setting given the extensive progress made in the country towards universal access to ART and the large number of older persons involved. Estimates suggest that by 2010 about 150,000 Thai parents will have a surviving HIV infected adult child on ART. In addition, most older age Thais continue to co-reside with an adult child and at more advanced ages depend on adult children for their material support and personal care. Many other developing countries, including in Asia, share these features of familial support for older-age parents with Thailand. Thus the results and the recommendations stemming from the present study are likely to be relevant for many other settings where ART is now becoming widely accessible to PLHA.

Methods

The results presented are drawn primarily from two sources: an ART Recipient Survey in which 912 adults on ART completed a short self-administered questionnaire at 18 distribution sites in five provinces and Bangkok and 108 extensive face-to-face interviews with parents of adult children on ART from all four regions of the country (Parent Interviews). Although the ART Recipient Survey is not based on a probability sample, it covered a wide range of settings with respondents recruited both from provincial and community hospitals in each sample province and two large hospitals in Bangkok. Comparisons with the national caseload of adult ART patients indicate that the sample is similar in terms of its gender distribution and the sources of government insurance used. Although the Parents Interviews were largely limited to cases where parents lived in the same locality as their adult child on ART, and thus to those who are particularly likely to be involved, the results are at least relevant for this substantial subset of parents. Also, since core members of PLHA support groups assisted in the recruitment of cases, most interviewed parents lived in localities where such groups were active. Thus the reported role of PLHA support groups as reflected in the Parent Interviews may be more extensive than it would otherwise be if recruited respondents had also included parents in localities not covered by PLHA groups.

Improved health and its consequences for parents

In the Parent Interviews, respondents reported major improvement in overall health of their HIV infected sons and daughters and large declines in a whole range of symptoms following ART initiation. The average number of 21 potential symptoms commonly associated with HIV/AIDS that were experienced declined from 7.2 just prior to ART initiation to only 1.5 by the time of interview. This in turn was associated with major reductions in parental caregiving and assistance. For example, of 16 potential caregiving tasks, the average number of parents that reported doing so declined from 4.2 prior to when their child started ART to only 1.6 at the time of interview. Moreover, the share of parents who reported that they provided any care declined from almost three-fourths to just over two-fifths. Parents, however, continued to provide psychological support.

Not surprisingly, parents reported a major reduction in their worries about the health of their HIV-infected adult children with 58 per cent saying they were very worried prior to the start of ART but only 14 per cent saying they were currently very worried.

Parents also reported major reductions in an array of expenses associated with their HIV-infected child. In addition, most of the adult children on ART according to the Parent Interviews were able to continue or resume economic activity with almost three fourths (73 per cent) reported as currently working and over half (56 per cent) as contributing to their parent's material support. While this represents declines from before their diagnosis of HIV status, when over 90 per cent were working and 70 per cent were providing support to a parent, it is in sharp contrast with the time before which ART became available, when disabling illnesses and death eliminated the possibility of filial support. Moreover, many parents can now anticipate old-age support from their children on ART in the future. In brief, the spread of ART in Thailand, by restoring the health of many PLHA and preventing the onset of serious illnesses in others, has resulted in reductions in the care and financial burdens placed on the parents and considerable improvement in parents' psychological well-being.

New contributions by parents

Widespread access to ART has also transformed the contributions that older age parents and other family members can make to the societal effort to cope with the epidemic. The ART Recipient Survey clearly documents that over four-fifths of adult ART patients in Thailand have a living parent. Moreover, more than 90 per cent live with close family members, including a third who co-reside with a parent. Since many others have parents living nearby, approximately half live with or in the same locality as a parent. Living with or nearby PLHA puts many parents and other family members in particularly advantageous positions to monitor if ART and other medications are being taken as required, remind the PLHA to take medications on time, remind them to keep appointments associated with treatment, and to accompany them to the health services involved. The ART Recipient Survey also shows that such assistance is by no means unusual, especially among parents and family members who co-reside with the PLHA. For example, just over 60 per cent of recipients who have a living parent and just over three fourths of those who live with a parent reported that their parent had reminded them either currently or in the past to take their medications. The Parent Interviews underscore the active role of parents in assisting with treatment adherence and reveal that they and other family members sometimes played a role in encouraging the PLHA to get tested for HIV and to seek ART treatment. Moreover, in those cases where the adult child on ART experienced periods of illness from side effects, parents often provided care.

In order to most effectively provide assistance with ART treatment adherence, it is important that those doing so have sufficient understanding of the treatment requirements. Results from the Parent Interviews, indicate that those respondents who received advice either on ART generally or on related caregiving for someone on ART had considerably better basic knowledge of the treatment and its requirements than those who did not receive advice. Quite likely much of this advice was received from health personnel or others involved in the ART programme during home visits or visits to health service outlets while accompanying their HIV infected adult child. Almost two-thirds of parents interviewed reported that their adult child on ART had received at least one home visit in connection with their treatment and that among those who were visited, 74 per cent were visited by a PLHA peer and 55 per cent by a hospital staff member. Moreover, the minority of parents who reported that they had attended meetings of PLHA support group meetings scored particularly high with respect to their ART knowledge.

Community reactions

Various arguments have been put forward, although rarely with systematic supporting evidence, concerning the impact of increased access to ART on reactions of others in the community to PLHA and their family members. Moreover, consideration is typically focused on stigma and little or no attention given to supportive and sympathetic reactions. Results from the Parent Interviews clearly indicate that not only did parents more frequently report positive than negative reactions both prior to the time that their HIV infected adult child started ART treatment and currently but also that negative reactions were considerably less common at the time of the interview than prior to ART initiation. Given that other changes likely occurred that could impact community attitudes towards parents of PLHA during the time respondents' adult children started ART treatment and the time of interview, it is not possible to attribute the reduction in negative community reactions to ART with certainty. Nevertheless, the results are in line with suggestions that the spread of ART contributes to improved reactions to PLHA and their families as visible symptoms disappear and PLHA resume more or less normal lives.

Little programmatic attention to family members

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 re-

source-limited countries. The most commonly advocated strategy involves programmes that recruit PLHA peers as treatment supporters. These efforts, often known as “buddy programmes”, are typically implemented through community based, PLHA self-help groups. The emphasis on the involvement of PLHA peers in facilitating adherence has very much been the case in Thailand. Although family members are sometimes mentioned in the context of treatment support programmes, they receive far less attention than PLHA peers. When they are mentioned, distinction is rarely made in terms of relationships to the person on ART and parents in particular are almost never specifically cited.

The relative lack of attention given to family members and particularly to older age parents in augmenting adherence is unfortunate. First, given the need for sustained lifetime adherence, parents and other family members often live with or nearby ART patients and thus are ideally positioned to provide sustained assistance over long periods of time. Second, they are often present not only on a day-to-day basis but also often at the specific time that medications need to be taken. Third, they typically have deep emotional reasons for wanting the ART patient to achieve and maintain good 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.

The almost total neglect of parents’ potential to assist could well be related to their older ages. Health professionals may assume that older persons, who often have low levels of formal education, are incapable of sufficiently understanding ART to provide useful assistance. Among the parents interviewed, however, neither low education nor problems with literacy appear to have been barriers to a basic understanding of what treatment adherence entails.

Combining PLHA peer and family efforts

In most cases, it is unrealistic to expect PLHA peers to assist on the same frequent and continuous basis that family members could. Still, home visits by PLHA peers can play an important role in facilitating family members’ effectiveness in assisting treatment adherence by providing appropriate information and training to them. Such efforts should not only concern the basic requirements of ART but also what side effects might arise and how to deal with them, especially since parents often are involved in care associated with side effects. PLHA 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 PLHA support groups are associated with hospitals as in Thailand.

In sum, the results presented in this report clearly document the mutually beneficial impact that widespread access to ART has on the well-being of both PLHA and their older-age parents. Undoubtedly other family members benefit as well. The results also underscore the need to incorporate close family members, including older-age parents, more explicitly into programmes intended to augment adherence to ART and to help facilitate their effectiveness as long-term adherence partners by providing them with adequate information, training and resources. Peers from community based PLHA groups can be particularly valuable and appropriate in this regard.

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Introduction

Almost three decades into the worldwide HIV/AIDS epidemic, older persons remain marginal in the discourse of the international and national agencies charged with dealing with it. Likewise older persons' involvement in relation to the epidemic is rarely addressed in the extensive social research on the epidemic that has been amassed. It is true that older persons, even if defined in terms of being 50 or older, represent a relatively modest share of the HIV/AIDS caseload although their share is growing as antiretroviral therapy prolongs survival of persons with HIV to older ages. The impact of the epidemic, however, extends well beyond those infected. Family members, including older age parents of HIV positive adults and grandparents of young orphans left behind, are particularly vulnerable and may be adversely affected emotionally, economically, socially, and physically. Moreover older age parents and other family members can contribute in important ways to how society copes with the epidemic especially through providing personal care, emotional support and material assistance to those who are infected (Knodel and VanLandingham 2002; Knodel, Watkins and VanLandingham 2003).

While the size of the older population that is HIV-infected may be relatively modest, the number of older persons who are affected as a result of an infected family member, especially an adult son or daughter, is far greater. The large majority of adults living with HIV/AIDS have one or both parents surviving and most of those who died of AIDS had a parent living at the time of their illness and death. Moreover, these parents are typically at advanced ages with relatively few under 50 and many in their 60s and 70s. Thus the number of older persons who lost an adult son or daughter to AIDS is likely to at least equal the total number of AIDS deaths and the number that currently has an adult child living with the disease is likely at least to approximate the size of the current adult HIV/AIDS caseload (Wachter, Knodel and VanLandingham 2002). If allowance is made for older persons other than parents, such as grandparents, uncles and aunts, who may also be affected by younger generation family members with HIV, the potential number is even greater.

Just a few years ago, in most low- and middle-income countries including Thailand, the onset of AIDS related illnesses led to a rapid decline in health followed by virtually certain death. In contrast

now, with the widening availability of antiretroviral therapy (ART), when infected persons become seriously ill, they can receive effective treatment and often regain reasonable health. Moreover, increased testing prior to the onset of symptoms permits ART in a growing number of cases to start even before opportunistic infections associated with HIV emerge. As a result, the adverse effects of the epidemic on family members of persons living with HIV/AIDS (PLHA) are likely reduced or at least significantly delayed. At the same time, effective use of ART requires strict life-long adherence to drug regimens, paying attention to diet and exercise, and dealing with potentially severe side effects. This creates new opportunities for family members, including parents of adults or grandparents of young orphaned children under treatment, to provide assistance especially in relation to treatment adherence.

The present report examines how the impact of the epidemic on older persons and their contributions to mitigating its consequences are being transformed in the context of widespread provision of ART in Thailand. Among the issues explored are how having a HIV infected adult child receiving ART affects parents' roles in care giving, providing psychological support, paying expenses and encouraging treatment adherence. The report also examines changes in parents' psychological well-being and in the reactions of other community members to their situation. The results and the recommendations stemming from them are likely relevant not only for Thailand but for many other settings where family members, including those of more advanced age, are similarly intimately involved with those on ART through living arrangements and support exchanges.

The Thai Setting

Intergenerational relations

As in much of the developing world, a norm of filial obligation underlies Thai intergenerational relations (Knodel, Saengtienchai and Sittitrai 1995). At the same time, parents feel obligations to ensure the well-being of their adult children. Exchanges of support and services between generations in both directions remain pervasive, a situation which conditions the involvement of older-age parents and the consequences for them when an adult child contracts HIV (Knodel and Chayovan 2008; Knodel et al. 2007). Living arrangements of older age parents and adult children are closely linked to this system of familial support with most older Thais either residing with or living nearby at least one adult child. Moreover a substantial proportion of adult children live with or near their parents. According to a 1995 nationally representative survey, almost half of the adult children of Thais aged 50 and over lived in the same locality as their parents and just over half of these co-resided with parents. In 2007, the proportion of adult children who co-resided with parents remained almost unchanged but the proportion that lived outside their parents' province had increased considerably indicating increased migration. The vast majority of adult children that live away, however, maintain close contact with parents.¹

Traditionally older persons have been supported and cared for by family members, particularly their children. Dependence on children for material support in old age remains strong. For example, 70 per cent of persons age 70 and older in 2007 reported that their children were their main source of income. At the same time, government sources of support for older persons are increasing. In 1999 the National Social Security System that covers private enterprise employees incorporated provisions for old age pensions and there

¹ Between 1995 and 2007, the share of children age 18 and over and of persons age 50 and over that co-resided with a parent declined only slightly from 24 per cent to 23 per cent. At the same time, the share that lived outside the province of their parents increased from 31.5 per cent to 38.5 per cent (original calculations from the 1995 Survey of Welfare of the Elderly in Thailand and the 2007 Survey of Older Persons in Thailand).

are plans to establish programmes in which farmers and informal sector workers can also participate. In addition, an old age welfare allowance programme that formerly targeted indigent elderly has recently been transformed into a virtually universal, if quite modest, social pension (Chantanusornsiri 2009; HAI 2009; Jitapunkul and Wivatvanit 2009; Knodel and Chayovan 2008). While these formal assistance programmes may somewhat reduce old age dependence of parents on their own adult children in the future, they are unlikely to supplant it any time soon. Thus for older age parents, having to care for and support an adult child in poor health represents a reversal of the traditional flow of intergenerational support at this stage of life. Moreover, losing an adult child to an illness such as HIV/AIDS can potentially threaten the security of older age parents in the future as frailty and chronic illnesses increasingly undermine their ability to care for and support themselves.

The Thai AIDS epidemic and response

Thailand was the first Asian country with a significant AIDS epidemic. The first cases were reported in the mid 1980s and were followed by a sharp rise in incidence (new cases) starting in 1988 and that peaked in 1992 (Revenga et al. 2006; UNAIDS/WHO 2008). Much of the increase was fueled by widespread commercial sex with most cases attributable to male clients of female sex workers. Vigorous government efforts, including promoting 100 per cent condom use at commercial sex establishments, succeeded in sharply reducing incidence. Adult prevalence, however, continued to rise, peaking at around 2 per cent in the mid to late 1990s (Ainsworth, Beyrer and Soucat 2003). According to UNAIDS/WHO (2008) estimates, by 2007, adult prevalence fell to 1.4 per cent with 14,000 children in addition to 600,000 adults living with HIV. Somewhat lower estimates have been proposed by others (Punyacharoensin and Viwatwongkasem 2009). During the progression of the epidemic, the predominant mode of transmission shifted from sex work to marital sex between spouses, particularly husbands to wives, and sex between men having sex with men (Analysis and Advocacy Project and Thai Working Group on HIV/AIDS Projections 2008). Intravenous drug use also played a part throughout the epidemic although, with the exception of the very first years, injecting drug users have accounted for only a relatively modest share of overall cases.

Besides substantial success in combating the epidemic, Thailand is exemplary in the provision of ART (ESCAP 2009). From relatively few cases before 2001, the majority of PLHA judged to be in need were receiving treatment by 2007. ART is available at no cost at over 1,000 sites through several government insurance schemes. In

general, to qualify for ART under the government programmes, HIV-infected adults need to either have a CD4 count under a particular threshold (typically 200) or be symptomatic of illnesses associated with AIDS regardless of CD4 counts. In 2007, 70 per cent of government insured patients were covered under the universal coverage scheme run by the National Health Insurance Office, 22 per cent were insured through the social security system which covers most formal sector employees, and 8 per cent used civil service insurance. The number of private patients receiving ART is unknown but is 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 PLHA peer support groups was initiated in which at least two members per group are paid to do counseling and make home visits. Among other things, the home visits are intended to provide appropriate information to family members about the importance of adherence (Kumphitak et al. 2004). The PLHA support groups in the programme are typically affiliated with hospitals that distribute ART and generally are part of "Continuum of Care Centers". Expansion of the programme is underway and by September 2009 incorporated over 350 groups. In addition there are a large number of PLHA support groups that are not formally associated with the programme but may also provide some form of assistance with treatment adherence [information provided by ACCESS, AIDS Access Foundation]. Most discussion of augmenting ART adherence in Thailand, including an extensive World Bank report, focus almost exclusively on the role of PLHA support groups and peer assistance with little mention of the potential role that family members could play (Family Health International 2007; National AIDS Prevention and Alleviation Committee 2008; Revenga et al. 2006). Relatively little attention is directed towards the contributions that family members, and especially older age parents, can and do play in assisting with treatment adherence. Indeed, this is a major issue that is addressed in the present report.

Estimates of older age parents potentially affected by HIV/AIDS

Since HIV infected adults in Thailand are predominantly in their 20s, 30s and 40s, most have living parents, many of whom are relatively old. As a result, the number of older age parents who experience the illness or death of an adult son or daughter (or a grandchild) due to HIV/AIDS is quite substantial. For these parents, the usual intergenerational caregiving situation is reversed, with adult children being the ones requiring care while their older age parents are in the position of being potential caregivers.

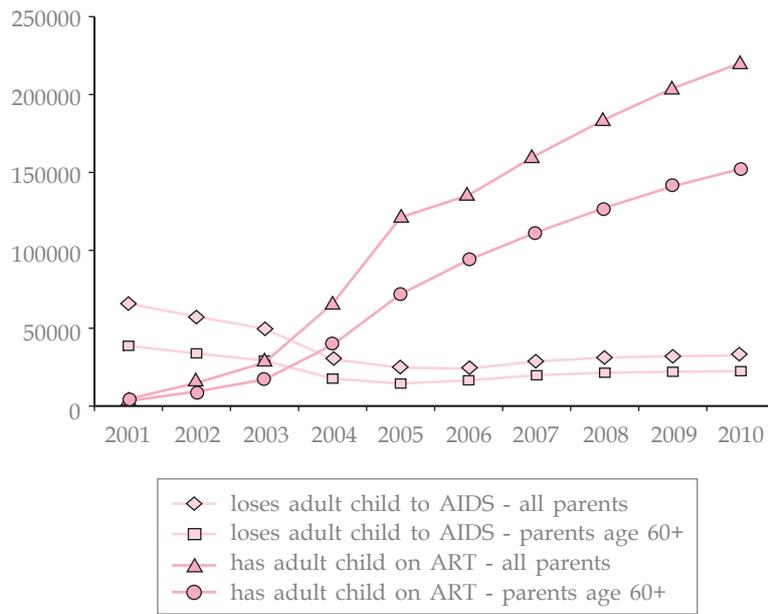
Figure 1 presents annual estimates and projections for 2001-2010 of the number of parents in Thailand who are potentially impacted by the epidemic through infections of their adult children. The estimates are based on recent projections of the epidemic that take into account the spread of ART (Analysis and Advocacy Project and Thai Working Group on HIV/AIDS Projections 2008). The methodology behind these estimates is described in the Appendix. The top panel shows both the number of parents who have an adult child currently on ART during the year and the number who have an adult child who died of an AIDS related condition. The number of parents who have an adult child on ART rises sharply during the decade reflecting an assumed rapid increase in access in Thailand throughout the decade. Thus by 2010, approximately 220,000 parents of all ages and over 150,000 parents age 60 and older are expected to have at least one adult child on ART.

The top panel also shows that the annual number of parents who will experience an adult child dying of AIDS is substantial. While the numbers are estimated to decline during the first half of the decade they are expected to increase modestly during the second half and by the end of the decade will exceed 30,000 for all parents and 20,000 for parents age 60 and over. The increase is due to the fact that while ART can prolong life, although within yet to be determined limits. Thus, some of the deaths that are postponed by ART earlier eventually occur later in the decade leaving parents with the loss of these children to AIDS.

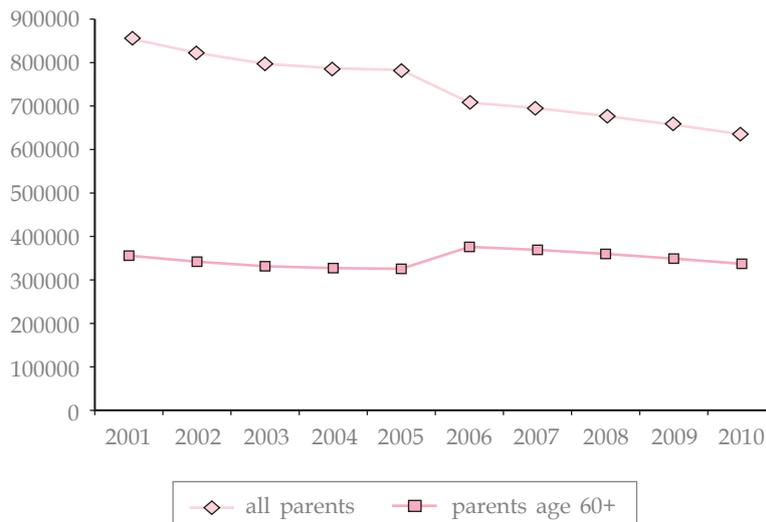
During the decade covered, new adult HIV infections are projected to decline by more than 50 per cent. However, as the lower panel of Figure 1 indicates, the overall number of parents with an adult child living with HIV/AIDS at year end, including cases that have not yet been diagnosed, declines only modestly and the number of elderly parents (aged 60 and over) with an HIV infected adult child remains relatively stable. The fact that trends in the number of parents of infected adults do not decline in the same proportions as new HIV infections decline reflects the expansion of effective treatment during the decade. Moreover, because the average age of those infected is increasing, higher shares of infected adults have parents who are at more advanced ages. Thus virtually no decline is evident in the number of old age parents who have an infected adult son or daughter during the decade. The absolute number of parents with an infected adult child declines from over 850,000 in 2001 to 633,000 by 2010 while the number of parents age 60 and over with an HIV infected adult child fluctuate around 350,000 during the decade. In brief, the number of Thai parents, including many who are elderly,

Figure 1. Estimated number of parents potentially affected by HIV/AIDS through the infection of an adult child, Thailand 2001-2010

A. Number of parents with an adult child who died of AIDS or is currently on ART



B. Number of parents with an adult child living with HIV/AIDS at end of year



who are at risk of being impacted by the AIDS epidemic through their grown children, and who could potentially contribute to caregiving and assisting with treatment is substantial.

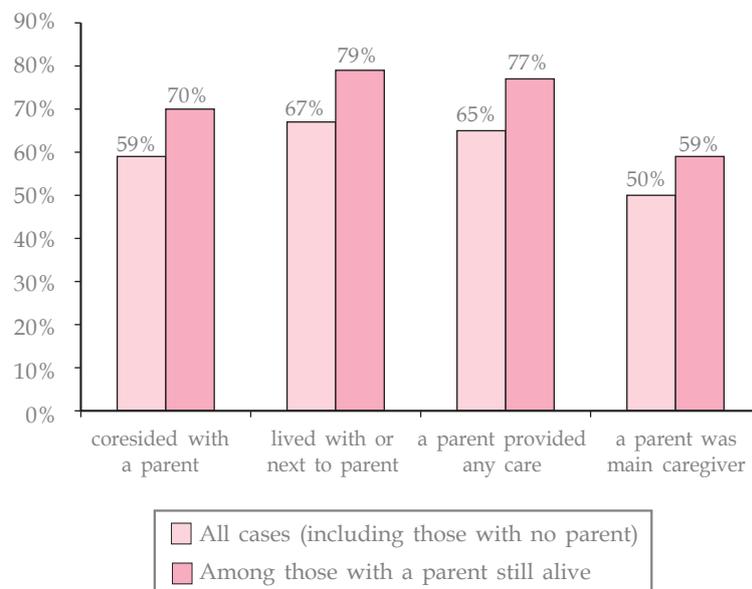
Parental involvement before the spread of ART

Considerable research on the role of older persons in the AIDS epidemic has been conducted in Thailand, much of it based on data collected between 1998 and 2001 that referred to experiences over several earlier years and thus prior to any appreciable access to ART in Thailand. This includes several qualitative research efforts (e.g. HAI 2005; Saengtienchai and Knodel 2003) and two major quantitative studies, one based on data provided by a survey of key informants (mainly local health providers) conducted primarily in the first half of 1999 and the other on a survey of parents who had lost an adult child to AIDS conducted in 2000 (Knodel et al. 2000 and 2002). The results clearly document that older-age persons contributed in important ways to the care and quality of life of their adult children or their grandchildren with HIV/AIDS but also were vulnerable to a variety of adverse consequences as a result. During the period to which the research refers, the general absence of access to ART meant that debilitating illness and death were virtually inevitable outcomes of HIV infection. This is quite in contrast to the present situation, in which most infected adults who need ART can receive treatment, a transformation that can greatly alter many of the consequences for the older-age parents of adults with HIV/AIDS that were documented in this earlier research. In this section, results of this earlier research are reviewed.

Living arrangements and caregiving

As Figure 2 shows, during the late 1990s, older Thais were extensively involved with their infected adult children through both living and caregiving arrangements. The majority of all adults who died of AIDS (59 per cent) co-resided with a parent at the terminal stage of their illness and fully two thirds either co-resided with or lived next to a parent. Moreover, parents assisted in personal caregiving for almost two thirds of adults who died of AIDS and were main caregivers for half. Among those who did not live with a parent or who did not receive parental caregiving, some had no surviving parent. If consideration is limited to adults who had at least one parent still alive, the results are even more striking. For example, among those with a surviving parent, co-residence at the terminal stage rises to almost 70 per cent and for almost 60 per cent, a parent was a main caregiver.

Figure 2. Living and caregiving arrangements at terminal stage of illness for adults who died of AIDS, Thailand, late 1990s



The high prevalence of terminal stage caregiving by parents is related to the fact that many adult children in Thailand, as discussed above, normally live with or nearby parents thus facilitating parental involvement in case of any serious illness. Also, return migration played an important part with between a third and two-fifths of adult children with AIDS who were cared for by their parents at the terminal stage having returned home from elsewhere. Such returns to the parental home often occurred at an advanced stage of illness when the infected son or daughter could no longer care for or support themselves (Knodel and VanLandingham 2003). Parental caregiving typically lasted only a few months but because it took place during the most debilitating stage of the illness, it often was particularly emotionally and physically draining for parents (Kespichayawattana and VanLandingham 2003; Saengtienchai and Knodel 2001).

Care for AIDS orphans

Caring for grandchildren who were orphaned because of AIDS has been another important contribution of older persons documented in the earlier research. In Thailand, however, more than half of adults

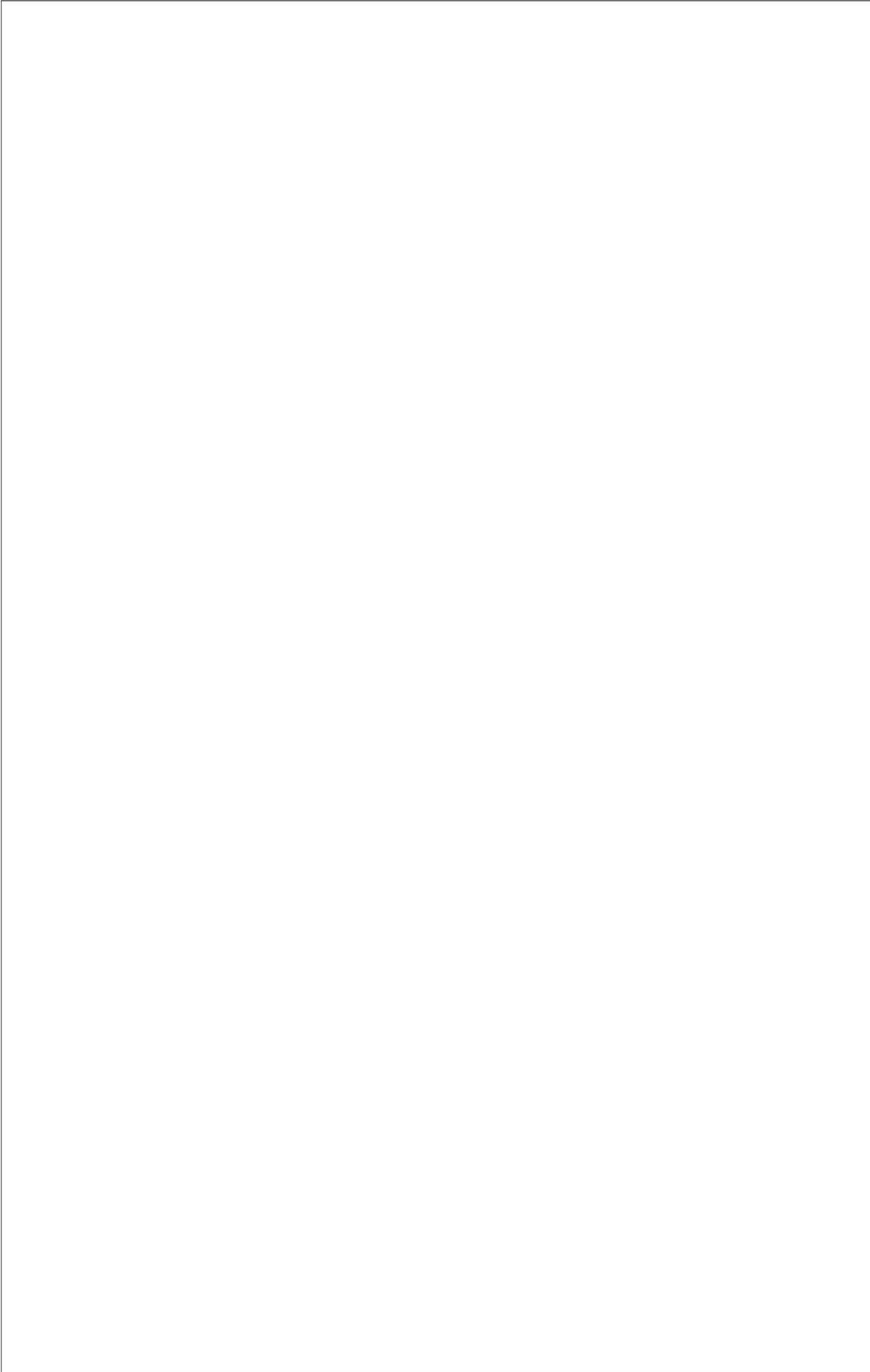
who died of AIDS were childless (Knodel and Saengtienchai 2004). A main reason for this is that about 30 per cent had never married and a substantial minority of those who did had no children at the time of death. Moreover, most deceased adult children who were themselves parents had only one child, reflecting the recent low fertility in Thailand. In addition, orphaned children typically have both surviving maternal and paternal grandparents but only one set typically adopts them. Thus, when all parents of adults who die of AIDS are considered, only a minority reported caring for an AIDS orphan. Still, when grandchildren did exist, grandparents were commonly involved in raising them, especially if both parents of the grandchildren had died.

Consequences for older persons

There are many different ways in which the illness and death of an adult child due to HIV/AIDS can affect the well-being of older-age persons (Knodel, Watkins and VanLandingham 2003). These include significant economic repercussions, the most immediate of which stem from expenses associated with treatment, caregiving, daily living and funeral costs as well as opportunity costs associated with time taken away from economic activity due to caregiving. If parents sell property or possessions or go into debt to cover expenses, or if the deceased child had been contributing to the parents' household income, the effect could be a sustained reduction in economic well-being. In addition, supporting orphaned grandchildren can involve significant expenses lasting for years. All of the routes to adverse effects of parents of persons infected with HIV, however, are likely to be mitigated or avoided if the health of the PLHA can be maintained or restored, a situation that becomes a real possibility once ART is widely accessible.

According to the survey of parents who lost an adult child to AIDS in the late 1990s, over half of those who played a main role in caregiving reported that it interfered with their economic activity (Knodel and Im-em 2004). However, only a little over a third said that this caused a lot of financial hardship likely reflecting the typically short period of intensive caregiving. Also, just under two fifths said the combined expenses for food, care, treatment and funerals that they incurred were a serious burden for them. To some extent, the financial impact during this was mitigated by government health insurance and social welfare programmes at the time as well as informal community funeral societies (Knodel et al. 2002). Although the health insurance at the time did not cover ART, this had little effect on the expenses of the vast majority of families since few at that time were aware of its existence. It did

however reduce the financial burden that other costs associated with health care for PLHA posed for them. According to the survey, among the 60 per cent of respondents who said health insurance paid for medical costs associated with their deceased adult child, over half said that it helped very much. In contrast, welfare payments targeting AIDS cases were far less important, with just under a fifth of respondents reporting that their deceased child received any and of those only a fifth said the payments helped very much in coping with the expenses (Knodel and Saengtienchai 2005).



Methods

Data for the present study examining the contributions of and consequence for parents in the context of widespread accessibility of ART are derived from two sources. The first consists of short anonymous self-administered questionnaires that were completed by adult ART recipients when they came for resupply of their medications. The second consists of detailed structured questionnaires administered in face-to-face interviews to parents of adults currently undergoing ART treatment. The two sources are intended to complement each other. The ART Recipient Survey can provide estimates of some basic parameters within which the detailed information about the involvement of parents with adult children on ART derived from the survey of parents can be placed.

ART Recipient Survey

Adult ART patients coming for resupply of their antiretroviral medications at 18 hospital sites in five provinces (Rayong, Surat Thani, Ubon Rachathani, Pitsanaluk and Lampang) and Bangkok were requested to complete a one-page anonymous self-administered questionnaire.² 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. Within regions the selection of particular provinces was in part based on where the two Thai principal investigators from the Chulalongkorn Faculty of Nursing had contacts who could assist in arrangements. The two hospitals in Bangkok were in part selected for the same reason.

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 caseloads while also choosing ones located at different distances from

² The questionnaire is provided as a report appendix at <http://www.psc.isr.umich.edu/pubs/pdf/rr09-686.pdf>.

the provincial capital. The number of target cases per site within a province was roughly proportional to the site's caseload.³ In Bangkok, only two hospitals were chosen since the caseloads at each location were very high. 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 was conducted under the auspices of the Chulalongkorn University Faculty of Nursing and 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 that participation was entirely voluntary. The research team extensively pre-tested the questionnaire to ensure it was readily comprehensible, easy to fill out, and could be completed in a few minutes. Information collected concerned the age and sex of the patient, the parents' living status, age and location, whether or not parents knew about the patient's treatment, and if parents assisted in several ways with treatment adherence. The patient was also asked with whom they lived and if persons other than parents helped remind them to take their medications

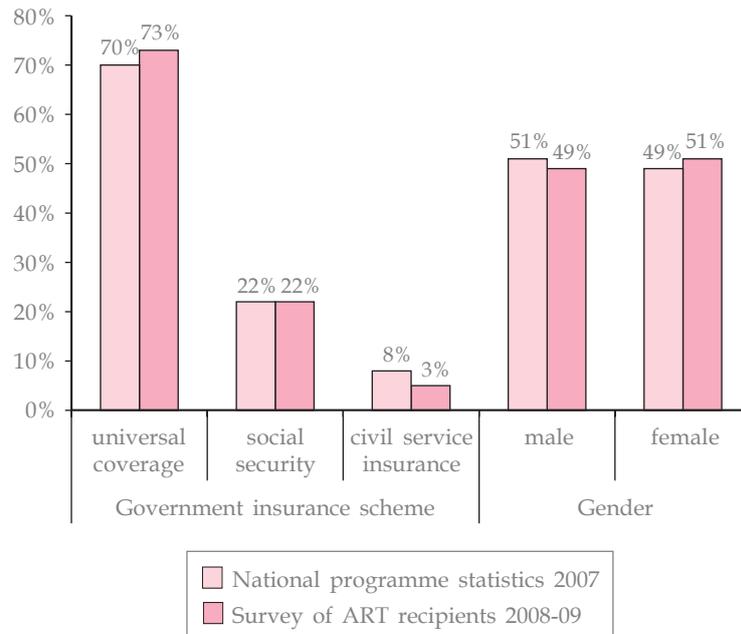
Response rates were not systematically recorded but nurses at each site were asked to summarize roughly how many patients declined to complete the questionnaire. They unanimously reported that almost every one asked was willing to comply. The high response rate is likely attributable to the very short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

Although the sample is purposive and to some extent one of convenience, 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 3 indicates, comparisons with the national pool of ART patients as represented in the government programme statistics regarding source of insurance coverage and gender indicate close correspondence with our sample.

Overall, the sample is almost equally divided between men and women as is the national caseload. A similar gender distribution is reported in a recent study of ART patients in four community

³ In one province, a third community hospital was included to compensate for insufficient cases available at another originally selected.

Figure 3. Comparison of national government programme statistics and ART Recipient Survey with respect to type of government coverage and gender of recipient, Thailand



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

Note: 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 that did not indicate the source.

hospitals in Chiang Mai (Le Coeur et al. 2009). The mean age of respondents is 38.5 with 50 per cent between ages 30-39. Only 9 per cent are below age 30 and 40 per cent are age 40 and over including 9 per cent age 50 and older. Although statistics on the age of the national caseload on ART are not publicly available, there seems little reason to doubt that the sample is reasonably representative in this respect as well.

Parent interviews

The second source of data consists of 108 detailed face-to-face interviews using a structured questionnaire with parents who have

adult children currently undergoing ART treatment. A copy of the questionnaire is available online (<http://www.phishare.org/documents/AIDSELD/8307/>). Data collection for this stage took place during September 2008 through February 2009. Respondents were identified and contacted through PLHA support groups affiliated with hospitals that distributed ART in eight different provinces located across all four major regions of the country. Since selection of respondents was completely independent of the ART Recipient Survey, none of the parents interviewed are likely to be parents of recipients who filled in the self-administered questionnaires.⁴ The PLHA support group explained the nature of our research to the parent and the adult child on ART and obtained their permission for the interviews in advance. The three principal Thai investigators conducted 28 of the interviews. The remaining 80 were conducted by eight nurses who, recently completing the Master's degree programme at the Chulalongkorn University Faculty of Nursing, had returned to their home provinces to resume work. The two principal investigators, who are also faculty of the programme, explained the questionnaire to the nurses, in most cases prior to their return to their home provinces, and in each location joined the interviewers for their initial interviews to provide additional individual training.

The original design called for selection of parents of adult ART patients who lived in the same locality (rural village or urban community). This restriction derived from the fact that we were locating parents for interview through PLHA support groups whose activities were focused on PLHA in their local area of jurisdiction. For this reason, we assumed we would only be able to reach parents who lived with or near the ART recipient in the same locality. This turned out to be the case in 95 (i.e. 88 per cent) of the 108 interviews. Of these, patients co-resided with their parents in 82 cases, lived next door in six cases, and lived further apart but still within in the same locality in seven cases. For the remaining 13 cases, however, the adult child on ART was living outside the parent's locality at the time of the interview. In five of these cases, the PLHA had been living with parents but subsequently left to seek work elsewhere. In the other eight cases, the PLHA appears to have

⁴ The eight provinces where parent interviews were conducted are Amnat Charoen, Chonburi, Chumphon, Lampang, Phitsanulok, Rayong, Trang and Ubon Ratchathani. Given that the parent interviews were largely in sites different than those covered by the ART Recipient Survey and that in the few common sites, the selection of parents was done separately, the chance of any matches between the two data sets is virtually nil. Since both the ART recipient survey and the Parent Interviews were anonymous, however, there is no way to directly check this assumption.

lived outside the parents' locality the entire time between learning of their HIV status and the time of the interview with the parents.

To ensure privacy, interviews were usually conducted at the home of the parents but out of hearing distance of any non-family members who might be nearby. For 55 of the interviews, the PLHA was present and in 24 they participated actively in answering questions about themselves. In the 27 cases where both parents were present, one was designated as the respondent (more commonly the mother than the father) although the other parent was free to help answer questions. When only one parent was present, it was usually the mother. Thus, overall, mothers were the primary respondents for 80 per cent of the interviews. Nevertheless, in all cases where the respondent was married and lived with the spouse, questions were asked about the spouse's involvement with the care and treatment of the adult child on ART regardless of whether or not the spouse was present at the interview. Thus information is available for both parents even though only one served as the respondent. As a result at least some information is available for a total of 166 parents (i.e. counting both respondents and their spouses).⁵

A substantial majority of interviews (77) involved parents who lived in rural areas with most of the remainder (24) being with parents in small towns (tetsabaan tambol). Only seven interviews were with parents in larger urban areas (tetsabaan muang) and none involved parents in Bangkok. Most respondents (62 per cent) rated their relative economic position as average but among the remainder, far more reported their situation to be below average (31 per cent) than above average (8 per cent).

Given that the sample of parents was one of convenience, there is no reason that the characteristics of the parents interviewed or their adult children on ART should resemble the broader population of equivalent persons. Nevertheless, similar to the sex distribution of the ART Recipient Survey respondents, the adult children on ART of the parents who were interviewed are relatively equally split between sons and daughters (47 per cent vs. 53 per cent). The adult children of the interviewed parents are somewhat younger than the ART recipient sample. Their mean age was 35.0 compared to 38.5 for the recipient sample. Also only 23 per cent were age 40 or older

⁵ The questionnaire included a number of questions about parental involvement both just prior to the time the adult child started ART and currently. Although it is possible in some cases that spouses of the 45 widowed respondents were still alive just prior to the time their adult child started ART, information was not asked about their involvement at that time.

compared 40 per cent of the ART recipient sample and fully 15 per cent were under age 30. This younger age distribution of ART recipients reported in the parent interviews is in part due to the fact that at least one parent of the recipient had to still be alive for the interview to take place, while the ART Recipient Survey included all adult recipients regardless of whether or not they had a living parent. However, the sample of adult ART recipients whose parents were interviewed is still 2.5 years younger on average than the subset of ART Recipient Survey respondents who had a living parent. At the same time the parents covered in the parent interviews were somewhat older than the surviving parents as reported in the ART Recipient Survey. For example, of those covered in the parent interviews, 39 per cent of mothers and 33 per cent of fathers were age 70 and older versus 18 per cent and 27 per cent among those reported in the ART Recipient Survey.⁶

As noted above, due to the recruitment method a particularly notable aspect of the sample is that it is heavily skewed towards cases in which the parents and ART recipient lived in the same community and in most cases in the same household. For example, in 76 per cent of the cases, the PLHA to whom the interview refers co-resides with parents and 88 per cent live in the same locality. This compares to only 40 per cent and 63 per cent respectively of adult respondents with a living parent in the ART Recipient Survey.⁷ This limitation is important to bear in mind when interpreting the results of the parent interviews. As results from the ART Recipient Survey presented below make clear, parents in such situations are likely to differ in the contributions they make compared to those who live at a greater distance from their HIV infected adult children. The same is almost certain to be the case as well with respect to the consequences that parents experience.

Finally, given that we were interested in making comparisons between the situation before and after the adult child started on ART and after (i.e. at the time of the interview), we wished to have cases in which there was sufficient time for a change to take place. Thus we recommended that only parents whose adult child had been on ART for a reasonable amount of time be selected. In about three-fourths of the cases the PLHA in question had been on ART for at least a year and in only six cases was the child on ART under six months.

⁶ The percentages reported for the parent interviews include all mothers and fathers, i.e. both respondents and their spouses.

⁷ Even if recipients in Bangkok are excluded (since no parent interviews took place in Bangkok), only 42 per cent of recipients with a living parent co-resided with a parent only 67 per cent lived in the same locality.

Results: ART Recipient Survey

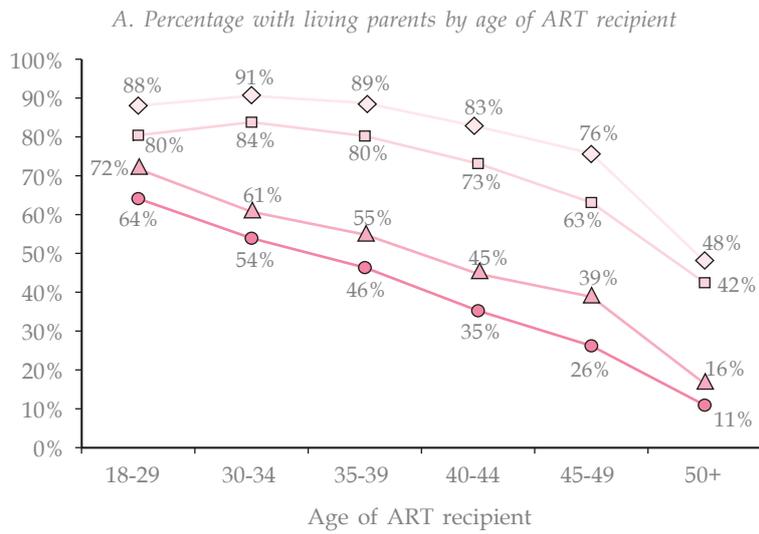
The ART Recipient Survey provides important information that permits placing the far more detailed results of parent interviews in a broader perspective. Of particular relevance is information concerning the extent to which adult ART recipients have surviving parents and where they live in relation to their parents as well as information on other family members with whom they live. In addition, the survey provides some very basic estimates that permit comparison of involvement in treatment adherence by parents and others.

Basic characteristics

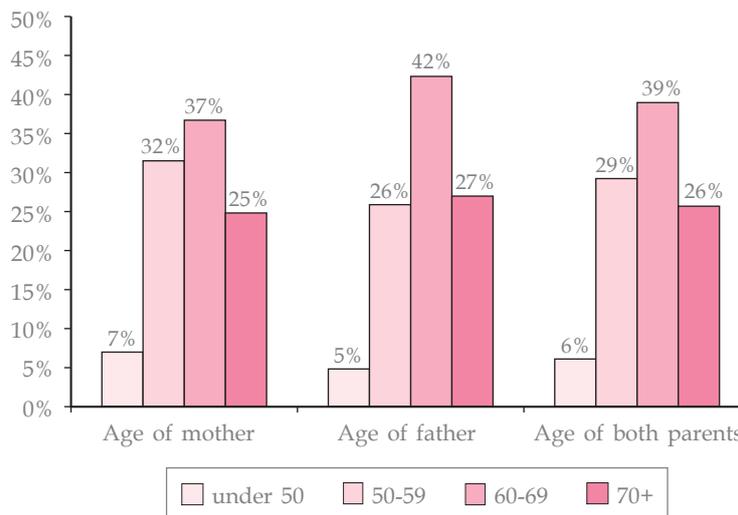
Results of the ART Recipient Survey indicate that the large majority (83 per cent) of adult recipients has at least one living parent and half of these (or 42 per cent of all recipients) have both parents still surviving. Given that previous research indicated that mothers are more likely than fathers to provide personal care to HIV infected adult children, it is significant that almost three-fourths of ART recipients still have a living mother (Knodel et al. 2001). As the top panel of figure 4 indicates, the proportion of adult ART recipients having surviving parents declines with age but even among those in their later 40s, 76 per cent have at least one surviving parent and 63 per cent still have a living mother. The proportion of ART recipients in any age group with a surviving father is substantially lower than the proportion with a surviving mother. This reflects the higher life expectancy among women than men and the tendency for men to marry women younger than themselves. As a result of the latter, fathers reach advanced ages where mortality is increased sooner than mothers do.

Given that the sample of ART recipients is limited to adults (i.e. age 18 or older), many of their surviving parents are in relatively advanced ages. As the bottom panel of figure 4 indicates, among all living parents only 6 per cent are under age 50 and almost two thirds are at age 60 and older with just over a fourth (26 per cent) being age 70 or older. Mothers tend to be slightly younger than fathers with almost 40 per cent of mothers under age 60 compared to less than a third of fathers.

Figure 4. Percentage of adult ART recipients with living parents and age of parents



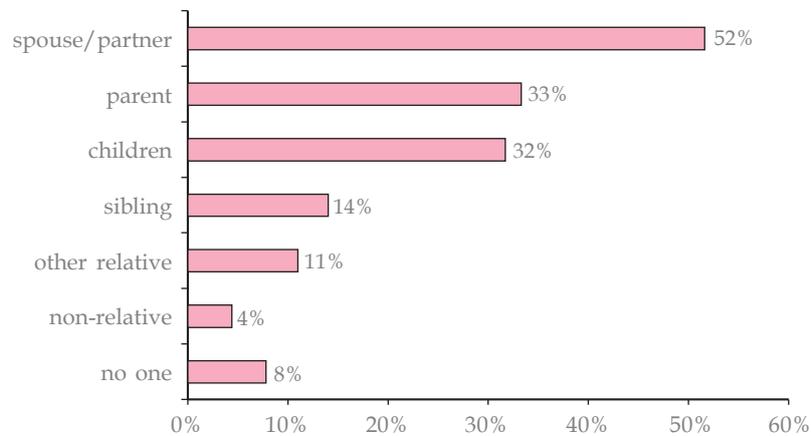
B. Percentage distribution of parents of ART recipients by age



Source: 2008 Survey of ART recipients

Figure 5 indicates the per cent of all ART recipients who live in the same household with persons of different relationships.⁸ Only 8 per cent of recipients live alone. They are most likely to share their residence with a spouse or partner, with just over half reporting being in this situation. Although the questionnaire did not distinguish between these two types of relationships, in the Thai context, the vast majority who answered affirmatively were likely to be in an intact marital relationship.⁹ Parents and children as co-resident household members are the next most common type of relationship, with roughly a third of recipients sharing households with each. ART recipients occasionally live together with siblings or other relatives but this is far less common than living with a spouse, a parent or child. Only a few ART recipients share households with non-relatives (and in almost 40 per cent of these cases there is also a family member in the household).

Figure 5. Percentage of adult ART recipients living with persons of specified relationships



Source: 2008 Survey of ART recipients

⁸ Since a recipient often lives with persons in more than one of the categories shown, the percents add to over 100.

⁹ In general, social recognition of a marriage does not require that it be officially registered. It is not unusual for persons who define themselves as married and who are recognized as such by other community members to hold a marriage ceremony but to wait a considerable time before registering their marriage officially (Chayovan 1989; Chayovan and Tsuya 2003).

As noted above, the different types of hospitals covered in the sample vary considerably in the types of areas from which their patients come. District hospitals largely serve rural clientele while provincial hospitals serve mainly persons living in or near the typically moderate sized cities that serve as provincial capitals. In contrast, recipients receiving their supplies at Bangkok hospitals typically live within the metropolitan area which is by far the most urbanized area in Thailand. As Table 1 shows, regardless of where the recipients go for service, there are only modest differences in the per cent that have a living parent. Four-fifths or more of the recipients at each of the types of distribution sites have at least one parent alive. Overall, just over half (52%) of all recipients indicated that not only do they have living parents but that they also lived in the same community as their parents. Moreover, as noted above, a third of the recipients co-reside with a parent. However, respondents from three different types of hospitals differ somewhat with respect to where they live in relation to their parents. Those who receive medications from district hospitals are the most likely, and those in Bangkok the least, to have a parent in the same locality. Also, those who go to Bangkok hospitals for resupply are least likely to co-reside with a parent even though they are more likely to still have at least one parent alive. When consideration is limited only to those

Table 1. Situation of parents of ART Recipients

| | Location of ART distribution site | | | |
|--|-----------------------------------|---------------------------------|-----------------------------------|--------------------------------|
| | All ART patients | District hospitals (i.e. rural) | Provincial hospitals (i.e. urban) | Bangkok hospitals (large city) |
| <i>Among all cases</i> | | | | |
| Number of cases | 912 | 423 | 332 | 157 |
| % having a living parent | 82.8 | 80.4 | 84.3 | 86.0 |
| % living in parents' locality ^a | 52.3 | 59.4 | 49.8 | 38.1 |
| % co-residing with parent ^a | 33.3 | 34.4 | 33.9 | 29.0 |
| <i>Among cases with a living parent</i> | | | | |
| Number of cases ^a | 755 | 338 | 275 | 133 |
| Location of parents (% distribution) | | | | |
| 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

Note: ^a Excluding a small number of cases in which information on the location of parents is missing.

recipients who have a living parent, Bangkok recipients are by far the most likely to live in a different locality than their parents (56 per cent) while district hospital recipients (i.e. those drawn mostly from rural areas) are clearly the least likely to do so (26 per cent).

It is interesting to note that the proportion of ART recipients with a living parent who co-reside with them (40 per cent) is substantially higher than the percentage in the general population of adult children of persons age 50 and above who co-reside with them (23 per cent) according to the nationally representative 2007 survey of the older population in Thailand. This higher percentage may reflect return migration of PLHA who had moved away but were prompted to return due to illness or due to the requirements of the government universal health coverage programme to receive ART services where one is legally registered.¹⁰ However, given that the ART Recipient Survey sample is not a probability sample, differences could also be due to sample design. In any event, the fact that levels of co-residence between ART recipients and their parents are substantial is important as such a situation considerably enhances the role that parents can play in supporting treatment adherence.

Treatment assistance

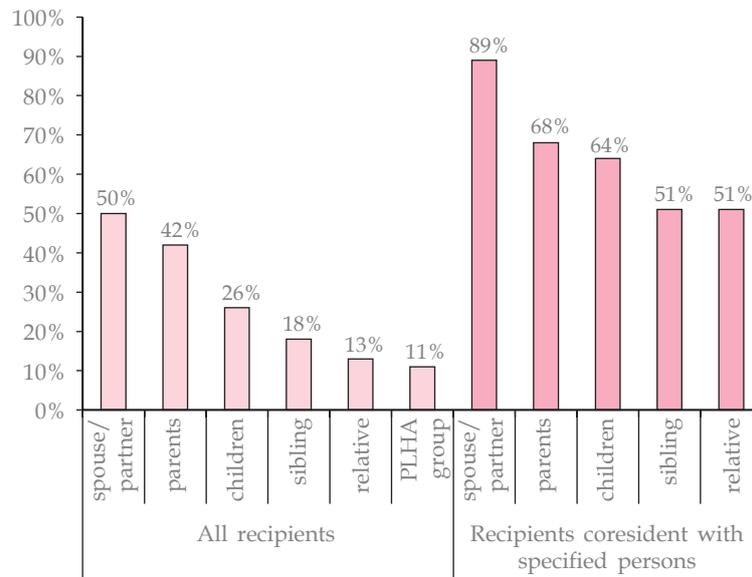
In order to assess the role of family members and others in assisting with treatment adherence, respondents were asked to indicate if different types of persons helped remind them to take their medicine. Respondents were also asked additional questions focused on assistance from parents, in particular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

Figure 6 shows the percentage of different types of persons who remind the respondent to take medications. Since co-residence greatly facilitates the ability to do so, results are shown both for the total sample and conditioned on living in the same household.¹¹ Among all respondents, 50 per cent indicated a spouse or partner reminds them to take their ART medications and 42 per cent that

¹⁰ It is not unusual for migrants in Thailand to retain their registration in their home district even though they move away on a long-term basis.

¹¹ Except for parents, information is based on a yes-no question that presumably refers to the present situation. For parents, the question asked the frequency of reminding. For Figure 2, responses that parents “never reminded” and “used to but not now” are treated as not currently reminding and all other responses are treated as currently helping remind regardless of frequency.

Figure 6. Percentage who currently remind ART recipient to take medications by relationship to recipient



Source: 2008 Survey of ART recipients

parents do. These are the two most frequent types of family members mentioned in this respect with other types of family members mentioned considerably less frequently.

Respondents were also asked about PLHA group members helping to remind them to take their medications. Overall only 11 per cent indicated that this is the case. This likely understates the importance of PLHA group members in the adherence process. Assistance by PLHA 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. In addition, PLHA group members likely concentrate on persons having difficulty with adherence thus rendering their contributions disproportionately greater than implied by the relatively low prevalence level (Lyttleton, Beesley and Sitthikriengkrai 2007; Revenga et al. 2006).

When results are conditioned on co-residing in the same household, large proportions of co-resident family members regardless of relationship are said to help in reminding the PLHA to take ART. This suggests substantial concern on the part of all co-resident family

members for the well-being of the respondent. Co-resident spouses (or partners) and parents are still the most common persons to remind respondents to take ART medications but co-resident children are close behind. Note that the frequency of reminding, however, in some cases may be only very occasional.¹²

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. Co-resident parents are by far most likely to be aware and those who live in a different locality are 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, the majority (58 per cent and 62 per cent respectively) indicated that their parents knew they were receiving ART.

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, a 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 per cent reported that parents used to remind them but no longer do so, presumably because it is no longer necessary. Thus, all together 61 per cent indicated parents helped them remember to take their medications either currently or in the past. At the same time, respondents who co-reside 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 per cent) of respondents with a living parent reported that a parent had reminded them to get their resupply and almost a fifth (19 per cent) reported that parents had taken them to get the medicines. A far smaller proportion (7 per cent) indicated parents helped prepare the medications, presumably because preparation is simple or unnecessary.¹³ In total, 54 per cent 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 co-reside or are younger.

¹² The frequency of reminding was only asked in relation to parents, so comparisons across family members are not possible.

¹³ The most common treatment consists of taking a single pill of combined medications twice a day, twelve hours apart (Kitkungvan, Apisarntharak and Laowansiri 2008).

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 | | | Age of youngest living parent | | | |
|--|---------|---------------------|---------------|-----------|-------------------------------|---------|---------|--|
| | | Co-resident | Same locality | Elsewhere | Under 60 | 60-69 | 70+ | |
| Number of cases ^a | 742-755 | 299-301 | 166-171 | 267-274 | 275-280 | 270-274 | 196-200 | |
| % whose parents know PLHA is on ART | 72.5 | 86.3 | 72.2 | 57.9 | 79.1 | 73.5 | 62.3 | |
| How often parent reminds PLHA to take medicines (% distribution) | | | | | | | | |
| 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 | 47.5 | 47.1 | 36.5 | |
| % ever taken to get medicines | 18.8 | 23.6 | 16.4 | 15.0 | 25.4 | 19.3 | 9.0 | |
| % ever had medicines prepared | 7.2 | 10.0 | 4.1 | 5.8 | 8.2 | 8.0 | 4.5 | |
| % had parents do any of the 3 tasks | 54.2 | 70.8 | 47.4 | 40.5 | 62.9 | 53.6 | 43.0 | |

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.

Results: Parent Interviews

As noted above, the 108 face-to-face interviews with parents of adults on ART provide far more detail than the ART Recipient Survey although on a considerably more limited and less representative sample. The structured questionnaire used was designed to explore both the consequences for the parents and their contributions to the care and support of their HIV infected son or daughter as well as how these have changed following their adult child's access to ART. As discussed in the methods section the sample is heavily skewed towards cases in which the parents and ART recipient lived in the same community and in most cases in the same household. This limitation is important to bear in mind when interpreting the results. Nevertheless, as the ART Recipient Survey makes clear, the situations in which PLHA live with or near parents are relatively common. Hence, even though the relevance of some of the parent interview results applies mainly to this subset of overall cases, the subset is quite large and thus of considerable importance.

Change in PLHA health

The parents who were interviewed were asked whether their son or daughter experienced a series of symptoms typically associated with HIV infection both currently and before starting ART. In some cases the son or daughter in question was present and assisted in answering. The most striking feature of the results, presented in table 3, is the very substantial decline in the presence of almost all of the symptoms listed.¹⁴ Overall, just over seven symptoms were experienced on average prior to the start of ART compared to only 1.5 at

¹⁴ All symptoms were asked about specifically except hair loss, skin discoloration and vision loss or blindness. Since these came up sufficiently often when asked about "other" symptoms they have been made separate categories. The questions concerning specific symptoms prior to the start of ART were skipped if the respondent indicated that the child was in good health at that time. Such cases are treated as experiencing no symptoms at that time. However, the questions concerning specific symptoms currently being experienced were asked regardless of the current health of the child. This could contribute to slightly underestimating declines in some of the symptoms. However, since cases in which adult children who started on ART but subsequently died are necessarily excluded from our study, their exclusion could bias results in the opposite direction.

Table 3. Percentage of PLHA experiencing symptoms associated with HIV and mean number of symptoms, before starting ART and at the time of parents' interview

| | Before ART | At time of interview | Absolute change ^a | Proportionate change |
|-------------------------|------------|----------------------|------------------------------|----------------------|
| % experiencing symptom | | | | |
| weight loss | 69.4 | 20.4 | -49.0 | -0.71 |
| feeling very weak | 66.7 | 17.8 | -48.9 | -0.73 |
| fever | 64.8 | 13.9 | -50.9 | -0.79 |
| headaches | 57.4 | 15.0 | -42.4 | -0.74 |
| problem eating | 52.8 | 15.7 | -37.1 | -0.70 |
| pain in the body | 50.0 | 18.7 | -31.3 | -0.63 |
| itchy skin | 48.1 | 22.2 | -25.9 | -0.54 |
| trouble sleeping | 47.2 | 15.0 | -32.2 | -0.68 |
| persistent cough | 44.4 | 5.6 | -38.8 | -0.87 |
| vomiting | 36.1 | 1.9 | -34.2 | -0.95 |
| shingles | 33.3 | 4.7 | -28.6 | -0.86 |
| diarrhea | 32.4 | 12.0 | -20.4 | -0.63 |
| confused | 29.6 | 11.2 | -18.4 | -0.62 |
| mouth sores | 29.6 | 4.7 | -24.9 | -0.84 |
| wounds | 22.2 | 3.7 | -18.5 | -0.83 |
| incontinence | 13.0 | 0.9 | -12.1 | -0.93 |
| hair loss | 7.4 | 1.9 | -5.5 | -0.74 |
| other symptoms | 6.5 | 2.8 | -3.7 | -0.57 |
| skin discoloration | 4.6 | 1.9 | -2.7 | -0.59 |
| vision loss or blind | 2.8 | 4.7 | +1.9 | +0.68 |
| Mean number of symptoms | 7.2 | 1.5 | -5.7 | -0.79 |

Source: 2008-09 parent interviews

Note: ^a Expressed in terms of change in percentage points for individual symptoms and number of symptoms for mean number of symptoms.

the time of the interview. The only symptom that showed an increase was the loss of vision, typically resulting in blindness. Apparently, this is one result of HIV that cannot be reversed and can only get worse. Although the number of such cases is relatively small, the symptom is an extremely serious one and thus merits attention.

The changes shown in table 3 are expressed both in absolute and proportionate terms. Excluding the case of vision loss, the prevalence of all 19 other symptoms declined proportionately by over half and, on average, by almost three fourths whether measured by the mean or the median. In almost all cases, the health of the HIV-infected adult child improved substantially. Clearly, ART has had enormous benefits for restoring the health of those who were symptomatic before taking it and maintaining the health of those who were not. This, in turn, can radically alter the situation with respect to the need for caregiving, including from parents and other family members.

In addition to information about specific symptoms, parents were asked about the overall health status of their adult HIV-infected child prior to starting ART and if and to what extent the health status had changed since then. For exactly half of the cases, parents reported that their adult child's health was poor or that the child was seriously ill before starting treatment. The other half was divided between those who said their child's health was good and those who reported that it was fair (i.e. there were health problems but not very serious ones). The fact that some of the adult children started ART when they were in good health reflects the fact, noted above, that the ART programme admits persons once their CD4 count falls below a criterion level (typically 200) even though they are still asymptomatic.

As table 4 shows, in over half of the cases, parents reported that their adult child's health had improved greatly since starting ART and many of the remainder reported that it was improved although problems remained. A modest proportion said that the health had not changed and a small per cent said it had worsened. The reported changes in health were clearly related to the initial health status when ART began. Thus for the half of the cases in which the health of the PLHA was poor at the start of treatment, there was no report that their health had worsened since beginning ART. Only 6 per cent reported little or no change in health. However for cases in which the PLHA was said to be in good or fair health at the start of treatment, 11 per cent were reported to have experienced a worsening of health and 22 per cent that health remained more or

Table 4. Percentage distributions of changes in health since PLHA started ART as reported by parent, by PLHA health status before starting ART

| | Health status just before starting ART | | |
|--|--|------|--------------|
| | Total | Poor | Good or fair |
| Number of cases | | | |
| Change in health since starting ART (% distribution) | | | |
| worse | 5.6 | 0.0 | 11.1 |
| same or little change | 13.9 | 5.6 | 22.2 |
| improved some but not completely | 24.1 | 29.6 | 18.5 |
| improved greatly | 56.5 | 64.8 | 48.1 |
| total | 100 | 100 | 100 |

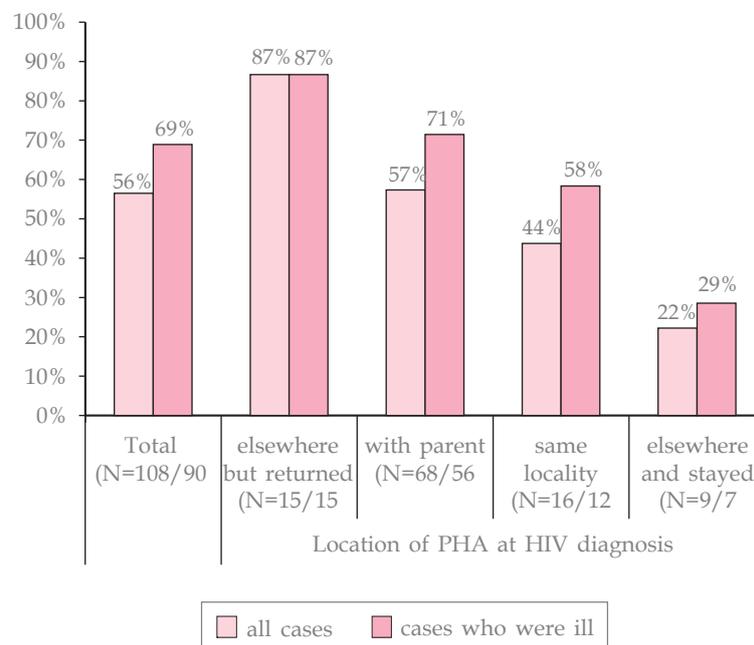
Source: 2008-09 parent interviews

less as before ART. In many of the latter cases, this reflects the fact that reasonably good health was maintained, very likely as a result of treatment and thus is a positive outcome.

Parental caregiving

As discussed above, research conducted prior to the widespread access of ART in Thailand found that parental caregiving to their HIV-infected adult children was common and substantial, especially at the terminal stage of AIDS when serious illnesses occurred. In the present study parents of adult children on ART who said their adult child had been ill prior to starting ART were asked if they or their spouse had helped care for their child during the time of illness. Parents who said the child was not ill prior to starting ART were not asked the question and are assumed to have provided minimal or no care. As figure 7 shows, among the total sample of 108 respondents, 56 per cent provided some care prior to the start of ART and among the 90 respondents whose adult child had been ill

Figure 7. Parental caregiving by location of PLHA at diagnosis



Source: 2008-09 parent interviews

(i.e. excluding the 18 cases who said that their child had been in good health before starting ART), 69 per cent provided some care.

As also evident in figure 7, the proportion that provided care, whether based on the total sample or on only cases in which the PLHA had been ill, is related to where the PLHA resided relative to the parents. The level of care was highest for the cases in which the PLHA was living outside the parents' locality at the time that their HIV status was diagnosed since returned. In all 15 of these cases the PLHA had been ill before starting ART and in all but one was living with the respondent (i.e. the parent) after returning. Most such cases likely involve PLHA who returned to their parental locality for care thus accounting for the very high percentage among them who received it. Among the remaining cases, the highest per cent for which parental care was reported is for those who were living with parents at the time of diagnosis and the lowest per cent by far for the small number of cases who remained outside the parental locality following diagnosis. These differences underscore the need when interpreting results from the parent interviews to take into consideration that the sample consists mainly of parents who lived with or nearby the adult child receiving ART.

In order to assess how ART has altered the situation, parents interviewed in the current study were asked if they or their spouses had performed any of 15 specific caregiving tasks for their adult HIV-infected child before the start of ART and if they were currently doing so.¹⁵ Results are presented in Table 5 and organized under four main categories of tasks relating to personal care, daily living activities, health care, and instrumental help.

The results make clear that the substantial improvement in the health of many of the PLHA following initiation of ART relieved parents from caregiving activities; the percentage of parents that had

¹⁵ All 15 tasks were asked about separately. Respondents were also asked if they or their spouse had done any other tasks not specifically asked about and responses were recorded in a residual category "other". The questions concerning tasks done prior to ART initiation were skipped if the respondent indicated in response to a prior question that the child was in good health when starting treatment. Such cases are treated as not doing the tasks at that time with the exception of assisting with going to health services which as explained in footnote 16 incorporates responses to a question regarding taking the PLHA to a doctor to improve the mental state that as asked to all respondents. Questions concerning specific tasks currently being done were asked regardless of the current health of the child. Thus, the results would likely understate declines in the percentage of parents doing the tasks.

Table 5. Percentage of PLHA for whom parent (respondent or spouse) provided care by type of task and mean number of tasks parents performed before starting ART and at the time of interview

| | Before starting ART | At time of interview | Absolute change ^a | Proportionate change |
|---|---------------------|----------------------|------------------------------|----------------------|
| % receiving type of care | | | | |
| <i>Personal care</i> | | | | |
| help with moving around | 25.0 | 8.3 | -16.7 | -0.67 |
| help bathe | 21.3 | 4.6 | -16.7 | -0.78 |
| help dress | 17.6 | 4.6 | -13.0 | -0.74 |
| help with eating | 16.7 | 1.9 | -14.8 | -0.89 |
| help go to toilet, | 16.7 | 3.7 | -13.0 | -0.78 |
| <i>Daily living assistance</i> | | | | |
| prepare food | 53.7 | 28.7 | -25.0 | -0.47 |
| launder clothes or bed linens | 30.6 | 16.7 | -13.9 | -0.45 |
| make bed or clean room | 24.1 | 9.3 | -14.8 | -0.61 |
| <i>Health care assistance</i> | | | | |
| help with medicines | 31.5 | 7.4 | -24.1 | -0.77 |
| massage | 30.6 | 10.2 | -20.4 | -0.67 |
| encourage exercise | 27.8 | 18.5 | -9.3 | -0.33 |
| clean wounds/change bandages | 6.5 | 1.9 | -4.6 | -0.71 |
| <i>Instrumental assistance</i> | | | | |
| go with to health services ^b | 65.7 | 30.6 | -35.1 | -0.53 |
| consult with health providers | 35.2 | 10.2 | -25.0 | -0.71 |
| help apply for benefits | 15.7 | 5.6 | -10.1 | -0.64 |
| Mean number of tasks ^c | 4.20 | 1.63 | -2.57 | -0.61 |

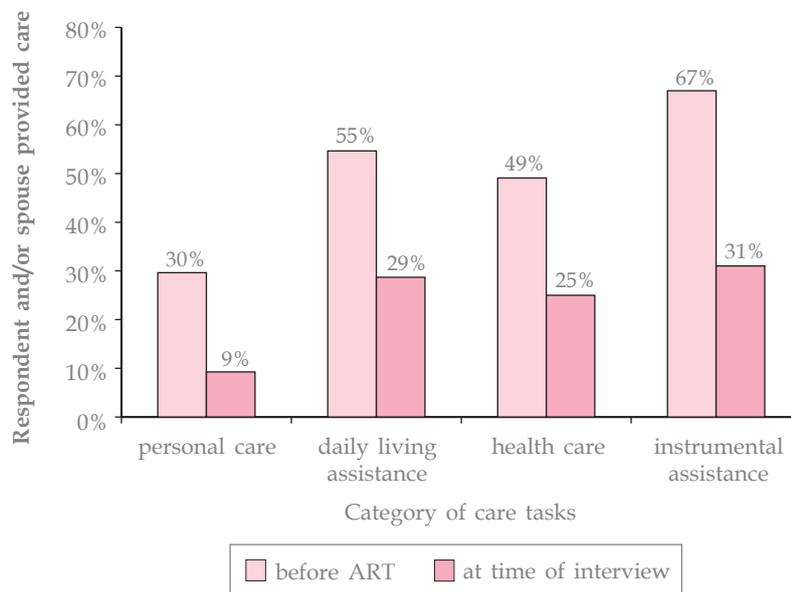
Source: 2008-09 Parent Interviews

- Notes: ^a Expressed in terms of change in percentage points for individual symptoms and number of symptoms for mean number of symptoms.
^b As described in footnotes 15 and 16 in the text, this item incorporates responses both in relation to caregiving and to psychological support.
^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" than those listed.

reported doing each of the specific caregiving tasks declined considerably after the initiation of ART. The declines shown in Table 5 are expressed both in absolute and proportionate terms. Proportionately, the prevalence of all but two of the 15 caregiving tasks declined by over half and on average the per cent doing the various tasks declined by about two thirds whether measured by either the mean or the median. Overall, the mean number of caregiving tasks performed by parents declined from 4.2 to 1.6 between the time before ART started and the time of the survey.

The contrast between the situation before their adult child started ART and the current situation with respect to the percentage of parents providing any of the tasks within the four main categories of care is summarized in Figure 8. Regardless of the category, the percentage of respondents who said they or their spouse were providing care currently is far lower than the per cent who said they had provided such care prior to the start of ART. Proportionately, the largest decline is with respect to personal care likely because the vast majority of the PLHA have 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 still providing at least some assistance. In some cases the assistance for daily living may not necessarily be related to the HIV or health status of the adult child as some of these tasks could be routinely provided by parents, especially for coresident children, in any event. 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.

Figure 8. Parental caregiving by category of care tasks, before ART and the time of interview



Source: 2008-09 parent interviews

Note: Results shown refer to the provision of one or more of the tasks included in the category as shown in table 5

Respondents who provided care for their HIV-infected adult child themselves or whose spouse did so either before the child started ART or currently, were asked about the time involved and the difficulty experienced providing the care. As table 6 shows, overall the percentage of cases in which a parent provided any form of care in relation to their child's HIV status is substantially lower currently than prior to the start of ART. This is also true after excluding tasks associated with instrumental care which unlike the other forms of care are likely to be done on an occasional rather than a daily or very frequent basis. Moreover, among those who provided care other than only instrumental tasks, both the time spent and the difficulty experienced is far lower currently than prior to the initiation of ART. Over two fifths of parents who provided care before their HIV-positive child started ART indicated they spent most of the day doing it and under a third reported that it involved only a short amount of time. In sharp contrast, less than a fifth who currently provided care spend most of the day doing so and for almost half it involved only a short amount of time per day.

In addition to the time spent, the difficulty of caregiving among parental caregivers has also declined very substantially. Prior to the initiation of ART, more than a third reported that the caregiving was very difficult and less than a third indicated that it was not difficult. In contrast, the majority of parents who currently provide care to their adult child on ART report that doing so is not difficult

Table 6. Time and difficulty of parental caregiving to adult HIV+ child before ART and at time of interview

| | Before ART | At time of interview |
|--|------------|----------------------|
| <i>Among total sample</i> | | |
| Number of cases | 108 | 108 |
| % providing any type of care | 73.1 | 42.6 |
| % providing care excl. instrumental care ^a | 56.5 | 31.5 |
| <i>Among those who provided care (excluding instrumental care)</i> | | |
| Number of cases | 61 | 34 |
| <i>Amount of time spent caregiving</i> | | |
| most of the day | 41.0 | 17.6 |
| a few hours a day | 27.9 | 35.3 |
| only a short time | 31.1 | 47.1 |
| <i>Difficulty of caregiving</i> | | |
| very | 36.1 | 11.8 |
| somewhat | 32.8 | 32.4 |
| not difficult | 31.1 | 55.9 |

Source: 2008-09 parent interviews

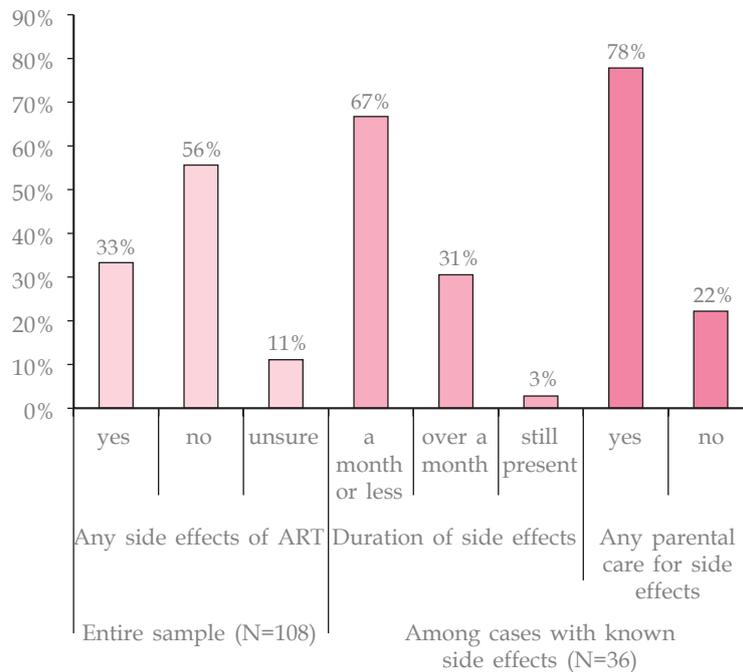
Note: ^a See table 5 for a list of instrumental tasks.

and only a little over a tenth indicate that the caregiving is very difficult. Thus, ART has not only greatly reduced the need for parental caregiving but it has also reduced the time and difficulty involved for those who do provide care.

One drawback of ART is that it is not unusual for persons undergoing treatment to experience adverse and sometimes severe side effects. Often the side effects are temporary and can be tolerated for a short period before they dissipate (UNAIDS IATT 2006). During the time side effects are being experienced, however, ART recipients need encouragement and sometimes care if the side effects are debilitating. In the parent interviews, we asked whether or not the adult child on ART had experienced side effects and, if so, how long they lasted and whether or not the parents (i.e. the respondent or spouse) had provided any care during the time the side effects occurred. Results are summarized in figure 9.

Overall, side effects were reported for a third of the cases. This may modestly understate the prevalence since 11 per cent of respondents were unsure about whether their adult child had experienced

Figure 9. ART side effects and associated care by parents



Source: 2008-09 parent interviews

any side effects. Among those cases where side effects were known to have occurred, they were generally of relatively short duration with two thirds lasting no longer than a month. At the same time, over three-fourths of respondents indicated that they or their spouse had provided some care during the period when the side effects were being experienced. Thus, parents appear to play an important role in dealing with side effects.

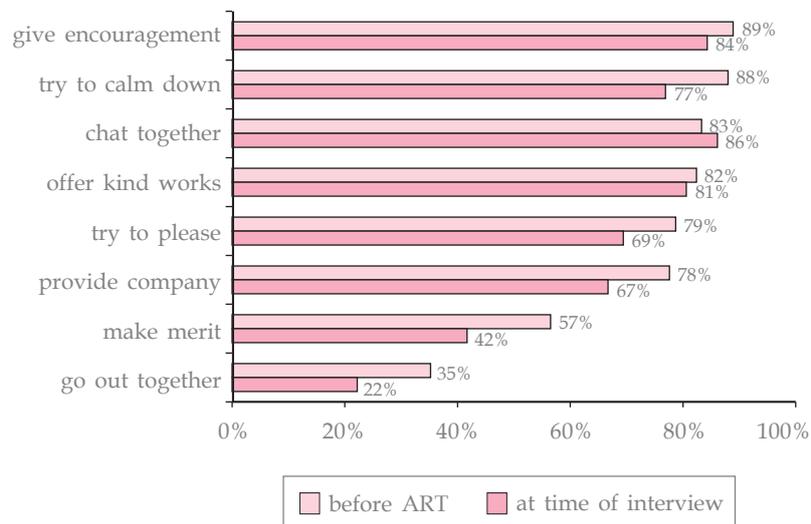
Psychological support and impact

Learning of HIV-positive status can have severe psychological effects not only on the PLHA but also on family members, including parents. This was likely to be especially devastating before there was widespread access to ART, when a HIV-positive diagnosis implied that certain death would follow before long as a result. In the interviews with parents, respondents were asked whether they or their spouse had done any specific activities that might be intended to improve their HIV infected adult child's mental state prior to the child's initiation of ART and if they currently were doing so. The specific activities related to trying to improve the psychological state of the PLHA and the percentage of respondents who indicated either they or their spouse had done them are presented in figure 10.¹⁶

Two main results emerge from figure 10. First, parents were quite active in trying to improve the mental state of their HIV-positive adult children. Second, this declined only modestly after the child initiates ART. Large majorities not only report that prior to ART initiation they gave encouragement, tried to calm down the PLHA, chatted together, tried to please the PLHA, and provided company before the start of ART but that they do so currently as well. Indeed, the mean number of psychological support tasks that parents reported only declined from 5.9 prior to ART initiation to 5.3

¹⁶ An additional question was if the respondent or spouse had taken the PLHA to see a doctor to improve the mental state. An examination of the results suggests that the question was interpreted by respondents as referring to taking the PLHA to a doctor for any reason rather than just for psychological help and thus it is not included. Instead it was combined with results for the specific caregiving tasks analysed above. In addition to the specific activities shown in figure 10, respondents were asked if they or their spouse had done anything else to help the mental state of the PLHA. Responses were recorded in a residual category "other". Only three affirmative response were recorded with respect to the time prior to when ART was initiated and none with respect to the current situation. Thus, results are not included in figure 10.

Figure 10. Parental psychological support before ART and at time of interview

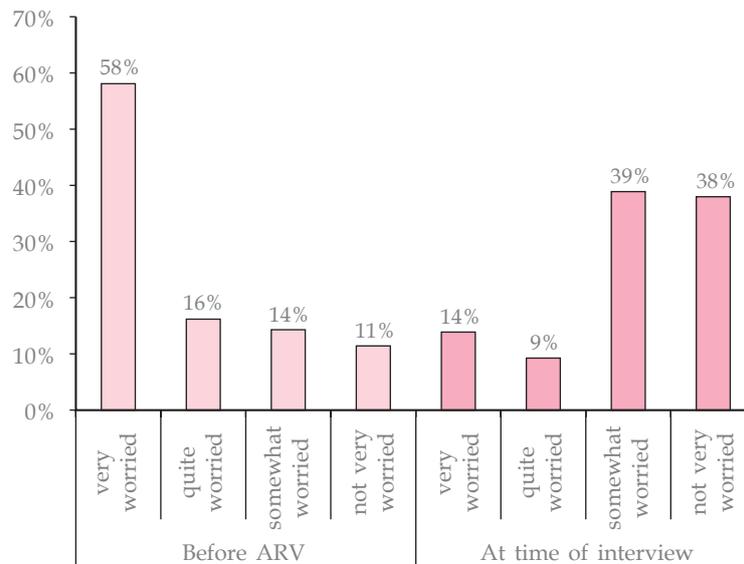


Source: 2008-09 parent interviews

currently (results not shown). Thus, unlike caregiving, the active role of parents in providing psychological support changes little as a result of starting ART. A partial exception to this is the decline in the percentage of parents who indicate that they “make merit” for their child currently compared to prior to the start of ART. In the Thai context, to “make merit” refers to taking actions, such as making contributions to Buddhist temples, that are believed to contribute to positive karma. It is possible that feeling the need to do so may be stronger when there is greater concern that the death of the PLHA is imminent than after starting ART, when health is restored or substantially improved. The least common of the eight activities is going out together perhaps reflecting generational differences in the type of outings that might be suitable for older age parents compared to their adult children.

Not only can learning of a HIV-positive status be psychological stressful for the infected person but also for the parents of the PLHA. In the interviews with parents of adult children on ART, respondents were asked how worried they were about their child’s health prior to the initiation of ART and currently. Figure 11 summarizes the results. Clearly parents are less worried currently than they were prior to ART initiation. At that time over half

Figure 11. Per cent distribution of the extent that parents worried about the health of their HIV infected adult child, before ARV treatment and at time of interview



Source: 2008-09 parent interviews

Note: Results for before ARV exclude three cases who were unaware of the HIV status of their adult child

indicated that they were very worried about their child's health and only 11 per cent indicated they were not very worried. In sharp contrast, only 14 per cent of respondents said that they were currently very worried about their child's health and almost two fifths indicate that they were not very worried currently. However it is important to note that their child's health is still a matter of concern for most parents and the majority continues to worry at least some in this regard. Undoubtedly, the fact that, in some cases, children still experience adverse symptoms associated with HIV and, perhaps even more importantly, because parents may be uncertain about how long the health benefits of ART will persist, is likely to sustain at least some anxiety about their child's future situation.

Treatment support

The parents who were interviewed were asked if they or anyone else encouraged the PLHA to be tested for HIV/AIDS or to start

ART and about their role in assisting their adult child with treatment support. The treatment support questions concerned the frequency with which the respondent or respondent's spouse reminded the PLHA to take ART medications on time and to get a resupply of medications and if they accompanied the PLHA to receive the resupply. In addition, in cases where the PLHA was taking other medications for HIV/AIDS related illnesses besides antiretrovirals if they helped remind their adult child to take them.

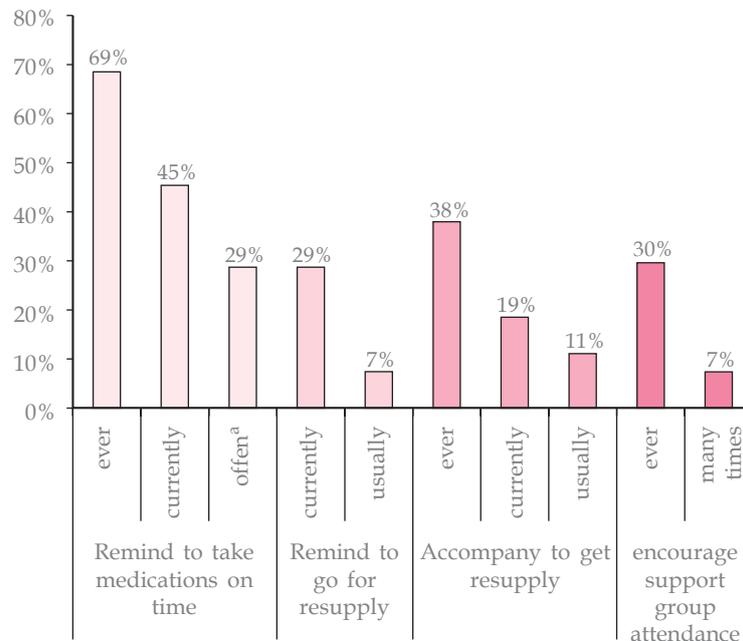
Parents and other family members or friends appear to have encouraged the PLHA to go for testing and to enrol for ART treatment in a substantial number of the cases. In a fifth of the cases, the parents interviewed reported that they or their spouse encouraged their adult child to get tested and in just over a third of the cases another family member or friend did so. Moreover, in 18 per cent of the cases, the PLHA received encouragement from a parent to start ART and in 43 per cent of the cases another family member or friend provided such encouragement.¹⁷

Once their HIV-infected son or daughter start ART treatment, parents are likely to be highly motivated for it to succeed and thus take an active role in encouraging adherence and related actions. In the parent interviews, respondents were asked whether they reminded the PLHA to take ART medications on time, to go for resupply and to attend PLHA support group meetings as well as if they accompanied the PLHA when going for resupply. These aspects of parents' involvement in ART support are summarized in figure 12.

Over two-thirds of respondents indicated that they or their spouse had at some time reminded their adult son or daughter to take their ART medications on time. However in a number of cases the respondent indicated having done this at the beginning but no longer did, presumably because their adult child was able to remember to take the medications on their own. Under half of the respondents (45 per cent) say that they or their spouse still remind their adult child to take their medications at least sometimes, though a substantial minority (29 per cent) report that they often

¹⁷ In some cases encouragement was provided by both parents and other family members or friends. In the small number of cases where the respondent did not know if anyone encouraged their adult child to get tested or if anyone encouraged going for ART presumably the parents did not provide encouragement and thus are included in the denominator on which the statistics on parents' encouragement are based. However they are treated as missing data in the statistics referring to encouragement by others since the respondent would not know if this occurred.

Figure 12. Parents' involvement in ART support for PLHA



Source: 2008-09 parent interviews

Note: ^a Often refers to at least several times a week.

remind their child to do so (i.e. at least several times a week) and thus play a relatively active role in promoting this critical aspect of treatment adherence.¹⁸

The parents interviewed also indicated that they sometimes remind their adult child on ART to go for resupply and even sometimes accompany them (in some cases likely providing transportation) to

¹⁸ Results from the ART Recipient Survey indicate that about 15 per cent of recipients with at least one living parent remind them on a daily or almost daily basis (see table 2) compared to 19 per cent of respondents (i.e. parents) in the parent interviews. This difference likely reflects the fact that the parent interviews were heavily skewed towards respondents who lived in the same locality as their adult child on ART. If the comparison is limited to only parents who live in the same locality for both samples, the results are quite similar with respect to the percents saying they daily or almost daily remind the PLHA to take ART medications (19 per cent versus 21 per cent respectively).

the hospital when they go for resupply. However doing this on a frequent basis is less common than reminding the PLHA to take their medications on time.¹⁹ Some parents also encourage their adult child on ART to attend PLHA group meetings which can be beneficial to providing peer support as well as provide useful information.

Only 14 parents (13 per cent of respondents) reported that their adult child on ART was also taking other medications for opportunistic infections. Among this small group, half said that they remind the PLHA to take these medications. Thus parents also appear to play a role in helping PLHA to take medicines other than those involved in ART although in such cases strict adherence to taking these medicines at specific times may be less critical than in the case of ART.

Financial assistance and impact

Prior research conducted in Thailand before ART was widely accessible found that parents of adults who became sick and died of AIDS often helped pay expenses for their adult child during the time of illness. This included paying for medicines, medical services, transportation and food. In addition, parents often incurred funeral costs following the death. Moreover, if the infected child had his own children, the parents of the PLHA might need to support these grandchildren both during the time of illness and after death. Such expenses could potentially drain limited financial resources and adversely affect their economic situation, especially for the poorest parents (Knodel & Im-em 2004).

In the interviews with parents of adult children on ART, respondents were asked whether they had contributed to major types of expenses associated with the situation of the PLHA both before ART was started and currently at the time of interview. The results, presented in Table 7, confirm that a substantial proportion of the parents interviewed had been helping pay expenses associated with their HIV-infected adult child prior to the start of ART but that the percentage doing so had decreased substantially by the time of the interview. Over two thirds of the parents interviewed indicated they helped with at least one type of the expenses shown prior to the start of ART compared to just over two fifths (44 per cent) currently. On average, of the six categories of expenses, the mean number with which parents provided financial assistance declined by half from 2.13 to 1.06 by the time of the interview.

¹⁹ This general pattern is also evident from the ART Recipient Survey results although the questions asked are not precisely comparable (see table 2).

Table 7. Parental expenses (by respondent or spouse) associated with PHLA by type of expenses before starting ART and at the time of interview

| % of cases in which parents (respondent or spouse) assisted with expenses in stated category | Before starting ART | At time of interview | Absolute change ^a | Proportionate change |
|--|---------------------|----------------------|------------------------------|----------------------|
| medicine | 29.6 | 6.5 | -23.1 | -0.78 |
| clinic or hospital fees | 34.3 | 9.3 | -25.0 | -0.73 |
| food | 59.3 | 33.3 | -25.9 | -0.44 |
| transportation | 55.6 | 26.9 | -28.7 | -0.52 |
| school expenses for PHA children | 32.4 | 27.8 | -4.6 | -0.14 |
| other expenses | 1.9 | 2.8 | 0.9 | 0.50 |
| any expense | 68.5 | 43.5 | -25.0 | -0.36 |
| Mean number of expense categories | 2.13 | 1.06 | -1.06 | -0.50 |

Source: 2008-09 parent interviews

Note: ^a Expressed in terms of change in percentage points for individual symptoms and number of symptoms for mean number of symptoms.

A reduction is evident in every one of the six categories shown. Proportionately, the largest declines in the percentage of cases of parents helping with expenses occurred in relation to medicines and clinic or hospital fees. In both cases, the percentages of parent assisting with expenses declined by around three fourths. This likely reflects the fact that their HIV-infected children are now covered by government insurance plans that pay for their ART. Paying for other costs also reduced substantially. The most modest change is with respect to assistance for school expenses for children of the PLHA, perhaps reflecting the fact that such expenses continue for a considerable period of time and that parents may assist their grandchildren from sons and daughters regardless of HIV status.

With respect to grandchildren, it is interesting to note that among the parents interviewed, in almost 60 per cent of the cases the PLHA on ART had children of their own and in just over half (52 per cent) of the cases, the respondent was helping with child care. In addition, in several other cases, the respondent had provided childcare but was no longer doing so. Helping with childcare may also contribute to the financial well-being of the PLHA on ART by making it easier for them to resume economic activity and earn a living. These results need to be interpreted, however, in the context of the fact that the sample of parents being interviewed is skewed

towards cases where the PLHA on ART lives with or very near parents. As a result a large majority of the cases involved grandchildren that also lived with or very near the respondent.

As noted in the discussion concerning the Thai setting, it is common for adult children to provide support to their parents and often be the main source of support when parents are at advanced ages. Thus, the fact that the parents of PLHA frequently provide financial assistance to their adult child represents somewhat of a reversal in the typical intergenerational exchange of material support at this stage of life. Indeed, prior to the widespread access to ART when HIV-infected adults were destined for premature death, parents had to deal with economic consequences that included not only the loss of current support from the infected child but also the prospect of losing any future support in their more advanced age when they would be unable to support themselves. The fact that ART significantly extends the lives of HIV-infected adult children alters this situation. Not only does ART permit many of the recipients to regain or maintain health sufficiently to resume economic activity, but it also opens up the possibility that they can provide current and future support to their older age parents.

Table 8 examines the economic activity of adult children on ART and their role in supporting their parental household both prior to being diagnosed as having HIV and at the time that the parents were interviewed. Prior to HIV diagnosis, over 90 per cent of these adult children had been economically active. Moreover, 70 per cent had helped support the parental household and over two fifths had been the main supporter. Again, these high levels of support for the parental household likely reflect, at least in part, the fact that the sample is skewed towards cases in which the adult children were living with or in the same community with parents.

By the time of the interview, the proportion of PLHA who were working had decreased to just under three fourths. Nevertheless, over half of the PLHA (56 per cent) were contributing to the support of the parental household and just over one fourth (27 per cent) were the main supporter. Although these percentages are lower than those prior to HIV diagnosis, it is clear that ART allowed most PLHA to either maintain sufficient health to continue working or regain sufficient health to resume work and even provide a considerable share of support to the parental household. These results are particularly impressive when compared to the likelihood that in the absence of ART many of the adult children would have either died or been suffering from a disabling illness preventing them from being economically active at all. Indeed, in a number of cases, the symptoms experienced prior to the start of

Table 8. Economic activity of HIV infected adult children and their role in supporting the parental household, prior to HIV diagnosis and at the time of parents' interview

| | Before HIV diagnosis | At time of interview |
|---|----------------------|----------------------|
| <i>Among all cases</i> | | |
| N of cases | 108 | 108 |
| % in which the PLHA worked | 93.5 | 73.1 ^a |
| % in which PLHA helped support parental household | 70.4 | 55.6 |
| % in which PLHA is main supporter of parental household | 43.5 | 26.9 |
| <i>Among cases in which the PLHA worked</i> | | |
| N of cases | 101 | 79 |
| Type of work (% distribution) | | |
| farming | 9.9 | 22.8 |
| labourer | 38.6 | 36.7 |
| factory or other employee | 33.7 | 13.9 |
| white collar ^b | 7.9 | 2.5 |
| self-employed | 9.9 ^c | 15.2 |
| other | 0.0 | 8.9 |
| total | 100 | 100 |

Source: 2008-09 parent interviews

Notes: ^a 63 per cent working fully and 10 per cent working partially
^b Professional, civil or military service, and clerical
^c Includes 1 case working for family business

ART had undoubtedly forced the PLHA to stop working. This is strongly suggested by the fact that almost three fourths (73 per cent) were seriously ill at the time of HIV diagnosis among the 26 cases in which the PLHA had worked before but was not working at the time of interview. This compares to only 43 per cent of the 75 cases in which the PLHA was working both at the time of diagnosis and when the parent was interviewed (results not shown in table).

Table 8 also indicates the type of work that PLHA had done at the time of diagnosis and at the time of interview in the cases where they were economically active. Most apparent is a decrease in the percentage that worked in factories or as employees elsewhere or in white-collar work between the two times and the increase in the per cent that was engaged in farming or self-employment. Presumably most of those in farming were working on their own or parents' land and thus, like the self employed, did not depend on someone hiring them, something for which their HIV status might have been a barrier.

Contact with ART related services

In order for parents to provide effective caregiving to an adult son or daughter with AIDS or to provide effective treatment adherence support for those who on ART, they need to be properly informed about these matters. The Thai AIDS programme encompasses 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 involved in the programme, as well as home visits by trained personnel associated with the health system, including 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. To assess the extent that parents of ART patients benefit from these possibilities, the parent interviews included a series of questions on home visits, participation in PLHA meetings, and receipt of advice on ART in general as well as on caregiving prior to and following the time that their adult child started ART.

As results in table 9 show, almost half of the parents interviewed indicated that they had received advice on caregiving before their adult child started ART and just over 60 per cent received advice on caregiving after their child initiated treatment. If the cases in which the PLHA had been in good health prior to starting ART are excluded – and thus presumably there was little or no requirement for caregiving – the percentages are somewhat higher. Over half of the parents interviewed also indicated they had received advice concerning ART generally. If we assume that information related to ART was received by those who reported that they received caregiving advice after ART was initiated, even though they did not report that they received advice on ART in general, then the percentage who received ART related advice is 65 per cent (not in table).

Information on who had provided advice was also collected. In some cases advice was received from multiple sources. This was particularly true with respect to advice on caregiving after ART was initiated and on ART generally, with over a third of respondents indicating advice on these matters from multiple sources. This likely reflects the fact that once ART is initiated, regular visits to the hospital by the PLHA are required and arrangements for home visits in connection with the treatment are often made. Of the parents who indicated that they received advice, the most common source was from hospital staff with respect to all three issues. However, in many cases PLHA group members also provided advice, especially with respect to caregiving after ART was initiated and ART generally. Much less commonly, parents reported receiving

Table 9. Receipt of advice on caregiving and ART by parent of PLHA

| | Advice on | | |
|--|-------------------------------|--------------------------------------|------------------|
| | caregiving prior to ART | caregiving after ART initiated | ART generally |
| Percentage receiving any advice | | | |
| All cases (N=108) | 47.2 | 61.1 | 55.6 |
| Excluding cases in which PLHA was in good health before starting ART (N=90) | 52.2 | 64.4 | 58.9 |
| Among those receiving advice, percentage receiving advice from ^a | | | |
| (Number of cases) | (51) | (66) | (60) |
| Hospital staff | 64.7 | 69.7 | 80.0 |
| Local health centre staff | 9.8 | 19.7 | 15.0 |
| PWA group member | 27.5 | 48.5 | 43.3 |
| Other | 13.7 | 6.1 | 3.3 |
| Multiple sources | 17.6 | 37.9 | 35.0 |

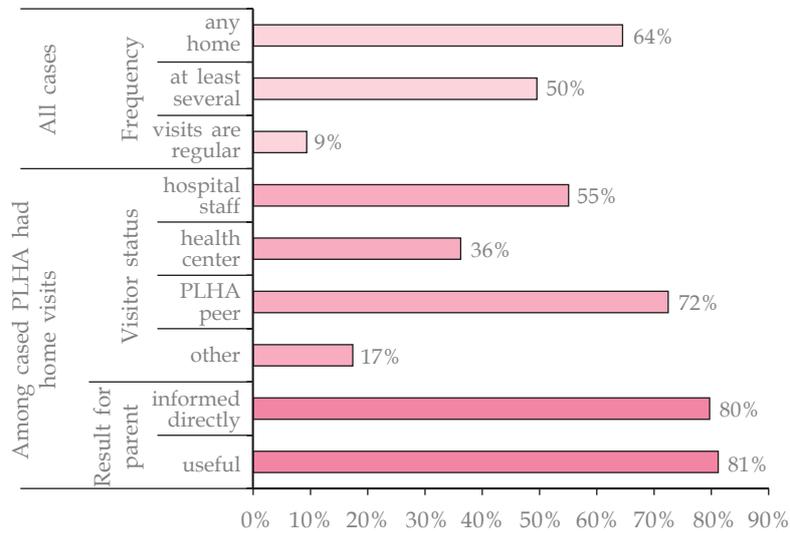
Source: 2008-09 parent interviews.

Note: ^a Percentages shown for specific sources are irrespective of whether advice was also received from any of the other sources

advice from local health center staff or other sources. The relatively high frequency with which PLHA group members are mentioned is likely in part a result of the study design given that PLHA support groups acted as intermediaries in the recruitment of the parents to be interviewed. Thus, the sample was drawn from areas where PLHA support groups existed and were active.

As Figure 13 indicates, almost two thirds of parents interviewed reported that their adult child on ART had received at least one home visit in connection with their treatment and half had received more than one visit. Receipt of home visits on a regular basis, however, were relatively rare. This likely reflects a strategy of home visit teams to concentrate continuing visits only in cases where the PLHA is having treatment difficulties. The most common source of home visits was from PLHA peers with almost three fourths of parents whose adult son or daughter had been visited reporting a visit from a PLHA support group member. Visits by hospital staff were also relatively common and occurred in over than half of the cases visited. Although less common, local health centre staff also made visits in some cases. Again, the high level of involvement of PLHA peers in home visits is likely in part a reflection of the fact that PLHA support groups served as intermediaries for recruitment of respondents for interview.

Figure 13. Home visits to adult child on ART



Source: 2008-09 Parent Interviews

Note: Percentages shown for visits from specific sources are irrespective of whether visits were also received from any of the other sources.

In cases where the PLHA received a home visit, four fifths of the parents (80 per cent) reported that during home visits they were directly given information about the treatment or their child's situation and thus were not just passive bystanders. Moreover, virtually the same proportion said that the information conveyed during home visits was useful for them. Thus, home visits play a useful role in assisting parents (and undoubtedly other family members) in providing treatment support.

Knowledge of ART

An important prerequisite for parents to effectively assist in ART treatment adherence is correct knowledge of the requirements. In order to assess the knowledge concerning ART among the parents we interviewed, we asked five questions: (1) How often do ART medications need to be taken? (2) Is it important to take ART medications at the same time every day? (3) How often do ART medications need to be resupplied? (4) Where does your adult child need to go for resupply? (5) Have you heard of tests for CD4 counts? Most parents seem to be informed about most of these matters. None of the respondents gave clearly incorrect answers to

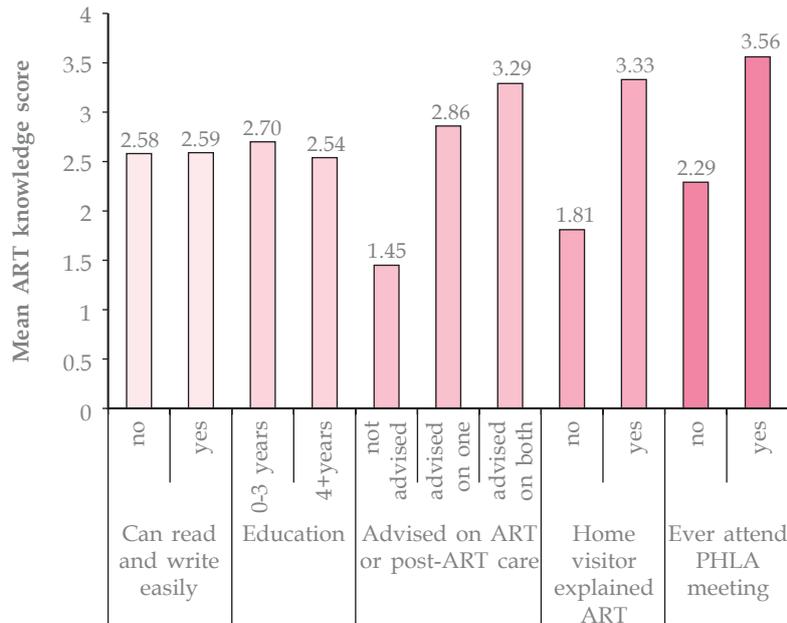
any of these questions but some stated they did not know. Overall 22 per cent did not know how often ART medications needed to be taken, seven per cent did not know that it needed to be taken at the same time every day, 19 per cent did not know the frequency of resupply, 4 per cent did not know where to go for resupply, and 49 per cent had never heard of CD4 counts.

In order to construct a single summary measure of ART knowledge, a score was calculated based on the responses to the five questions. A respondent received one point for each correct or plausible answer to the first four questions and an additional point if they had heard of CD4 counts. For each of the first four questions which they indicated they did not know the answer, one point was subtracted from their ART knowledge score. If they had not heard of CD4 counts they also lost one point. In the few cases where respondents said that ART medications only needed to be taken once a day, no point was added or subtracted since it is uncertain whether the answer is correct. Although the common version of medications currently distributed in Thailand requires two daily doses, some recipients could be taking a version that only requires one daily dose. Potentially, the score could vary from -5 to +5. The actual range was from -3 to +5 with a mean score of 2.6. A fifth of respondents achieved a score of 5 and 60 per cent had a score of 3 or higher. Only 28 per cent had a negative or zero score.

Figure 14 shows the average knowledge score of respondents according to the literacy and education of the respondent and according to receipt of advice, information given during home visits, and attendance of PLHA support group meetings. About a fourth of respondents had either no formal education or had not completed the basic primary education (grade four at the time most would have gone to school). However completing basic primary education did not necessarily ensure sustained literacy. Thus, only a little more than half could read and write easily and the remainder were either completely illiterate or had difficulty reading or writing. Low education and poor literacy, however, appear not to be barriers to understanding the basic requirements of ART as reflected in the ART knowledge score.

In contrast, receipt of advice or information related to ART is strongly associated with ART knowledge. Those parents who received advice on ART generally or on post-ART caregiving clearly scored better than those who did not. Moreover, those who received advice on both matters scored modestly better than those who received advice on only one of these matters. Also, parents who received information about ART treatment from programme personnel making home visits scored considerably higher than those who were not informed during a home visit themselves or whose infected adult child did not receive a home visit. Those parents who

Figure 14. 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 ever attended a PHLA support group meeting



Source: 2008-09 parent interviews

attended a PLHA support group meeting scored considerably better with respect to ART knowledge than those who had not, possibly indicating that attending such meetings proved instructive. As the results presented above indicate, low levels of education and problems with literacy did not prevent parents from knowing the basic requirements of ART; what seems to matter is receiving information or advice from programme personnel or through programme-related activities. Again, although it is not possible to assign causality to this association, the connection seems quite plausible.

Table 10 addresses whether ART knowledge is associated with treatment support as reflected in reminding the PLHA to take their medications, to go for resupply, and to accompany the PLHA when going for resupply. Based on their knowledge score, respondents were classified into three categories (low, medium, and high) of knowledge levels. There appears to be an association between knowledge and two of the three aspects of treatment adherence

Table 10. Frequency of parents reminding PLHA to take ART and frequency of parents accompanying PLHA to obtain resupply, by level of ART knowledge

| | Total | ART knowledge score ^a | | |
|---|-------|----------------------------------|--------|-------|
| | | low | medium | high |
| Number of cases | 108 | 28 | 38 | 42 |
| Frequency parents remind PLHA to take ART (% distribution) | | | | |
| often | 28.7 | 21.4 | 31.6 | 31.0 |
| sometimes | 16.7 | 10.7 | 21.1 | 16.7 |
| at first not now | 23.1 | 17.9 | 21.1 | 28.6 |
| rarely/never | 31.5 | 50.0 | 26.3 | 23.8 |
| total | 100.0 | 100.0 | 100.0 | 100.0 |
| Frequency that parents remind PLHA to go for resupply of medications (% distribution) | | | | |
| usually | 7.4 | 0.0 | 13.2 | 7.1 |
| occasionally | 21.3 | 32.1 | 15.8 | 19.0 |
| rarely/never | 71.3 | 67.9 | 71.1 | 73.8 |
| total | 100.0 | 100.0 | 100.0 | 100.0 |
| Frequency parents accompany PLHA to get resupply (% distribution) | | | | |
| usually | 11.1 | 0.0 | 13.2 | 16.7 |
| occasionally | 7.4 | 10.7 | 10.5 | 2.4 |
| at first, not now | 19.4 | 10.7 | 10.5 | 33.3 |
| rarely/never | 62.0 | 78.6 | 65.8 | 47.6 |
| total | 100.0 | 100.0 | 100.0 | 100.0 |

Source: 2008-09 parent interviews

^a Low knowledge includes respondents whose score was 1 or lower; medium knowledge to those with scores of 2 or 3; and high knowledge to those with scores of 4 or 5.

support. Respondents with a low level of knowledge concerning ART were distinctly less likely than those with medium or high levels to often remind the PLHA to take ART medications and far more likely to rarely or never remind them to do so. Moreover, parents with low levels of knowledge were also less likely than those with better knowledge to accompany the PLHA to obtain a resupply of ART medications and far more likely to rarely or never do so, especially in comparison to those with high levels of knowl-

edge. The relationship between knowledge level and the frequency with which parents reminded their adult children to go for resupply is less clear, although those with low knowledge are less likely to usually do so than those with better knowledge.

While it is possible that better knowledge promotes efforts that parents make to provide treatment adherence support, it is also possible that the causality runs in the opposite direction. Thus, it may be that those who are more motivated and active in encouraging their adult children to adhere to the requirements of ART learn more about it as a result. Nevertheless, it seems plausible that the causality runs in both directions and that better informed parents are more effective in providing treatment support than those who know little about ART.

Community reaction

Persons on ART and their families including their older age parents live in communities where reactions of neighbours and other community members to their situation can either help or hinder their quality of life. A great deal has been written about the stigmatization of persons with HIV/AIDS including “secondary stigma” that extends to their family members and caregivers (Ogden and Nyblade 2005). However, reactions of others in the community are not necessarily negative. They can also be rather sympathetic and supportive. Moreover, the nature of community reaction undoubtedly varies across settings and over time. Research in Thailand and Cambodia has found that, while negative community reaction is not absent and may have predominated at early stages of the epidemic, more recently positive reactions tend to be more common than negative ones (Knodel et al. 2010; VanLandingham et al. 2005).

There is a considerable literature indicating that the stigma associated with the disclosure of HIV-positive status is a barrier to accessing ART by those needing treatment (Posse et al. 2008). Far fewer studies have examined how the spread of ART has impacted stigma or community reaction more broadly. The limited studies and discussions that treat these issues argue in both directions. Some suggest that access to ART reduces stigma and discrimination, including observations with reference to Thailand (Lyttleton, Beesey and Sitthikrienkrai 2007; Maman et al. 2009; Wolfe et al. 2008). This can occur because ART often eliminates the physical signs and symptoms of AIDS that trigger negative reactions by

others in the community. Yet, others have argued that effects of ART on bodily appearance may perpetuate stigma (Ezekiel et al. 2009). One study in the United Republic of Tanzania suggested that provision of ART leads to blaming attitudes because others in the community believe by restoring health, PLHA can continue to engage in sexual activity that spreads HIV (Roura et al. 2009). Still others suggest that, because ART programmes result in increased disclosure of HIV/AIDS, they thereby increase exposure to stigma and discrimination in the community (Apinundecha et al. 2007; Liamputtong, Haritavorn and Kiatying-Angsulee 2009). Whatever is the impact of community reactions towards PLHA, quite plausibly these may also extend to their family members, particularly parents, given their frequent involvement in caregiving during periods when their HIV infected adult child is severely ill and symptomatic.

Presumably, reactions from others will only become apparent if others are aware of the situation. As table 11 shows, parents who were interviewed indicated that it was common for family members to have been aware of the PLHA's HIV status prior to ART initiation. In less than half of the cases, the neighbours knew of the HIV status and in only about a third of the cases were community members in general aware of the situation. By the time of the interview, however, awareness of the PLHA's HIV status was not only virtually universal among family members but was also considerably more widely known among neighbours and other community members than prior to ART initiation.

For cases in which respondents indicated that either neighbours or other community members were aware that their adult child was infected with HIV at the time, they were asked if they themselves or their spouses (i.e. the parents of the PLHA) had experienced various reactions as a result prior to when ART was initiated as well as currently. The series of questions covered both positive and negative reactions. Consistent with previous research in Thailand on community reaction to older age parents of PLHA, positive reactions are reported substantially more frequently than negative ones both before the start of ART and the time of the interview. Thus, prior to ART initiation, among cases where awareness of their adult child's HIV status extended beyond just family members, approximately two thirds of the respondents indicated that others in the community showed sympathy or concern about their situation and visited. In about half of the cases, the respondents also reported that they received food or other gifts from neighbours or other community members. The situation with respect to positive reactions was fairly

Table 11. Community awareness of adult child's HIV status and reactions experienced by parents

| | Before ART | At time of interview |
|--|-------------------|----------------------|
| Percentage of cases in which at least some of the following were aware of the HIV status of the respondent's adult child | | |
| family members | 80.0 ^a | 99.1 |
| neighbours | 42.9 ^a | 76.2 ^a |
| community members in general | 34.7 ^b | 67.0 ^c |
| Among cases in which at least some neighbours or community members were aware of HIV+ status of adult child | | |
| % experiencing positive reactions | | |
| sympathy or concern | 63.0 | 75.0 |
| visits | 67.4 | 65.8 |
| receipt of food or other gifts | 51.1 | 50.7 |
| any of above | 73.9 | 77.6 |
| % experiencing negative reactions | | |
| avoidance of visits or contact | 35.1 | 13.1 |
| gossip about PLHA or family | 47.1 | 28.3 |
| blamed for adult child having HIV/AIDS | 28.6 | 19.7 |
| any of above | 45.0 | 30.8 |

Source: 2008-09 parent interviews

Notes: ^a Excluding 3 cases in which the respondent was unsure
^b Excluding 7 cases in which the respondent was unsure
^c Excluding 8 cases in which the respondent was unsure

similar at the time of the interview with little change in the percentage that reported visits or receipt of food or gifts and a modest increase in the proportion who indicated that other community members expressed sympathy or concern. Overall about three fourths of respondents reported experiencing at least one of the positive reactions both before ART was started and at the time of the interview.

Reports of negative reactions were not lacking, especially prior to when a respondent's adult child had started on ART. Almost a third of parents at that time indicated that in situations when others in the community were aware that their child had HIV, some had avoided visiting or contacting them and almost half reported that there was gossip about their child or family. In a little more than a fourth 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, the percentages reporting each of these negative reactions were substantially lower and overall less than a third

indicated that they were experiencing any of the three negative reactions. Hence the predominance of positive over negative reactions was considerably greater when the infected child was undergoing ART than prior to when their adult child started ART.²⁰

The reduction in negative community reactions cannot be attributed to ART with any certainty since other changes may well have been occurring between the time respondents' adult children started ART treatment and the time of interview that resulted in reducing stigmatizing attitudes and beliefs. Nevertheless, the results are far more in line with the suggestions reviewed above that the spread of ART contributes to improved reactions to PLHA and their families rather than the opposite. Results from the interviews with parents clearly documented that major improvements in health and reduction in visible symptoms were experienced by PLHA undergoing treatment allowing many PLHA to resume more or less normal lives. Together, these changes quite plausibly reduced fears among other community members concerning risk of becoming infected through casual contact with the PLHA or their family and caregivers.

²⁰ Note that the reactions reported at the time of the interview includes a number of cases who had not reported reactions before ART started since at that earlier time it was less common for others in the community to be aware of their adult child's HIV status. However, even if comparisons of community reactions prior to the start of ART and at the time of the interview are limited to respondents who reported reactions at both times, results are similar. For example, among those reporting reactions at both times, 72 per cent reported at least one positive reaction at the time of interview and 30 per cent reported at least one negative reaction. Thus, there is little change in the percentage reporting positive reactions and a substantial decline in the percentage reporting negative reactions between prior to the time ART started and the interview.

Conclusions and Policy Implications

Universal access to affordable antiretroviral therapy for HIV-infected persons is a high priority endorsed by the United Nations and major donor agencies. Substantial progress is being made towards this goal in low- and middle-income countries and in some, including Thailand, coverage already reaches the majority of those in need (UNAIDS 2008; ESCAP 2009). This has greatly altered not only the lives of PLHA themselves but also the impact of the epidemic on their families, including their older age parents. Many of the previous adverse consequences on those affected that resulted from the debilitating illnesses associated with AIDS and inevitable death that followed have been significantly reduced or substantially delayed. 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 only medical attention but long term social and psychological support as well, including encouraging and monitoring treatment adherence (Beals et al. 2006; Hope and Israel 2007). Ensuring that medications are taken regularly and on time, that appointments are kept to get resupplies and essential tests, and that an appropriate diet is maintained over prolonged periods of time poses a major challenge both for PLHA and the programmes providing their treatment.

Previous research on the impact of the AIDS epidemic on older persons as parents and relatives of infected prime age adults and as grandparents of young orphaned children left behind has been quite limited, especially considering the large numbers of older persons involved. Nevertheless, the results that have emerged, including those from research based in Thailand, make clear that many parents of PLHA experienced a range of adverse consequences especially with respect to their emotional and material well being (Knodel and Im-em 2004; Knodel and Saengtienchai 2004). Yet, their needs that arise from their situation were rarely addressed by programmes intended to mitigate the epidemic's impact (HAI 2008). At the same time, their contributions to how societies coped with the epidemic, especially through parental caregiving to their infected adult sons and daughters and to providing foster care to their orphaned grandchildren, have been considerable (Knodel and VanLandingham 2002; Knodel and Saengtienchai 2004; Knodel, Watkins and VanLandingham 2003). The present report, based on a

survey of adult ART recipients and interviews with parents of adults on ART in Thailand, documents how the widespread access of ART has transformed the situation.

Major findings

Parents interviewed in the present study reported major improvements in overall health of their HIV infected sons and daughters following ART initiation and large declines in a whole range of symptoms that they were suffering. This in turn was associated with major reductions in the parental caregiving and assistance that was previously needed although parents continue to provide psychological support to their children on ART. Not surprisingly, parents reported a major reduction in their own worries about the health of their HIV-infected adult child. Parents also reported major reductions in an array of expenses associated with their HIV-infected child. In addition, because most of the PLHA on ART were able to continue or resume economic activity, many parents continue to receive material support from them and can anticipate old age support in the future when their own needs become greater. This is in sharp contrast to the earlier situation when debilitating illness and certain death eliminated the possibility of any such filial support from an adult son and daughter with HIV. In brief, the research on which the present report is based makes clear that the spread of ART in Thailand, by restoring the health of many PLHA and preventing the onset of serious illnesses in others, has resulted in considerable improvement in their older-age parents' psychological well-being and reductions in the care and financial burdens placed on the parents. Similar benefits undoubtedly have also extended to other affected family members.

Widespread access to ART has also transformed the contributions that older age parents and other family members can make to the societal effort to cope with the epidemic. The ART Recipient Survey clearly documents that over four fifths of adult ART patients in Thailand have a living parent. Moreover, over 90 per cent live with close family members, including a third who co-reside with a parent. Since many others have parents living nearby, approximately half live with or in the same locality as a parent. Living with or nearby places many parents and other family members in particularly advantageous positions to monitor if ART and other medications are being taken as required, to remind the PLHA to take medications on time, to remind them to keep appointments associated with treatment, and even to accompanying them to the health services involved. In addition, the ART Recipient Survey also shows that such assistance is by no means unusual, especially

among parents and family members who co-reside with the PLHA. The interviews with parents underscore their role in these respects and reveal that many are actively involved in assisting with adherence. Moreover, in those cases where the adult child on ART experienced periods of illness from side effects, parents often provided care. In addition, parents and other family members played a role in encouraging the PLHA to get tested for HIV and to seek ART treatment. Although the parents interviewed were largely limited to cases that lived in the same locality as their adult child on ART, and thus are particularly likely to be involved, the results are at least relevant for this substantial subset of parents.

In order to most effectively provide assistance with ART treatment adherence, it is important that those doing so have sufficient understanding of the treatment requirements. Results from the parent interviews indicate that those respondents who received advice either on ART generally or on related caregiving had considerably better basic knowledge of the treatment and its requirements than those who did not receive advice. Quite likely, much of this advice was received from health personnel or others involved in the ART programme during home visits or visits to health service outlets while accompanying their HIV-infected adult child. Moreover, the parents who reported that they had attended meetings of PLHA support group meetings scored particularly high with respect to their ART knowledge.

Policy implications

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 and Kegels 2008). The most commonly advocated strategy so far has involved programmes that recruit PLHA peers as treatment supporters. These efforts, often known as 'buddy programmes', are typically implemented through community based, PLHA self help groups (Burrage and Demi 2003; Hope and Israel 2007; Marino et al. 2007; United Nations 2008). The emphasis on the involvement of peers in facilitating adherence has very much been the case in Thailand (Family Health International 2007; Lyttleton, Beesey and Sittthikrienkrai 2007).

Although family members are sometimes mentioned in the context of treatment support programmes, they receive far less attention than PLHA peers (e.g. Ogden, Esim and Grown 2006). When they

are mentioned, distinction is rarely made in terms of relationships to the person on ART and parents in particular are almost never specifically cited (see e.g. Hope and Israel 2007; Nischal, Khopkar and Saple 2005; Mills et al. 2006; UNAIDS 2008; Ware et al. 2006). 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 including Thailand. 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. Among the parents interviewed, however, neither low education nor problems with literacy appear to have been barriers to a basic understanding of what the treatment adherence entails. Moreover, a recent study in Cambodia provides evidence that despite little education, older-age parents of PLHA there had considerable understanding of ART (Williams et al. 2008).

The relative lack of attention given to family members and older age parents in particular in augmenting adherence is unfortunate. First, given the need for sustained lifetime adherence, parents and other family members who live with or nearby ART patients are ideally positioned to provide sustained assistance over long periods of time. Second, they are present not only on a day-to-day basis but also often at the specific time that medications need to be taken. Third, they 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 for their assistance. 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 PLHA peers to assist on the same frequent and continuous basis that family members could do so. Still, home visits by PLHA peers can play an important role in facilitating family members' effectiveness in their efforts to assist treatment adherence by providing appropriate information and training to them. Such efforts should not only concern the basic requirements of ART but also what side effects might arise and how to deal with them, especially since parents often are involved in care associated with side effects. PLHA peers can also provide other critical supplemental support, including the occasional monitoring of the family's situation and by acting as intermediaries between the family and the health system, especially where PLHA support groups are associated with hospitals as is the case in Thailand.

The importance of the role that PLHA support groups could play in assisting parents and other family members in helping with treatment adherence is underscored by the results from the parent interviews that indicate that efforts at adherence support among parents are associated with better knowledge of ART which in turn is associated with home visits and attendance of PLHA group meetings. Moreover, the predominance of positive over negative reactions by others in the community and the apparent decline in negative reactions after ART is initiated suggests that such assistance can occur in a largely supportive atmosphere. PLHA peers and health providers involved in the ART programme in Thailand are often already aware from their own experiences of the potential of parents and other family members to assist in treatment adherence. Systematic recognition of this potential and guidance on how best to harness it, however, are needed and would almost surely contribute to the programme's success.

Programmes 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 and Bangsberg 2006). This includes taking into account family relationships and living arrangements. Recommendations about the best approaches based on research developed in countries in the West may well be less appropriate in the context of the developing world (Mills et al. 2006). In comparison, the Thai setting shares important features with many other developing countries that are critical for understanding the potential role of the family in assisting in ART treatment adherence. This is particularly so in the case of neighbouring countries in South-East Asia, which have much in common with Thailand with respect to family structure, intergenerational relations, and cultural underpinnings and thus are settings where older age parents and other family members are likely to have similar potential in helping cope with the AIDS epidemic in the era of ART. Elsewhere in Asia and even beyond, the Thai experience is likely to hold useful lessons. For example, the crucial role of the family in dealing with the epidemic within a context of community support has also been noted for sub-Saharan Africa and yet the family's role there also receives little recognition from governments, NGOs and international donors (UNRISD 2009). The relevance of the present study thus extends well beyond Thailand to many other countries in the region that face the challenges posed by rapidly expanding testing, treatment, and care programmes related to the AIDS epidemic but suffer shortages of financial and human resources.

In sum, results presented in this report clearly document the mutually beneficial impact that widespread access to ART has on the well-being of both PLHA and their older-age parents. Undoubtedly, other family members benefit as well. The results also underscore the need to incorporate close family members, including older-age parents, more explicitly into programmes 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 PLHA groups, the focus of most existing adherence augmentation programmes, can be particularly valuable and appropriate in this regard. By working together, their joint efforts could significantly contribute to the success of ART programmes in Thailand and elsewhere.

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Appendix

Estimates of the number of parents potentially impacted by
an adult child with HIV/AIDS, Thailand 2001-2010



Appendix

Estimates of the number of parents potentially impacted by an adult child with HIV/AIDS, Thailand 2001-2010

This appendix describes the calculation of annual estimates for 2001-2010 of the number of parents potentially affected by HIV/AIDS in Thailand. Estimates are made for three categories:

- 1) parents who have an adult child living with HIV/AIDS at year end
- 2) parents who have an adult child on ART at year end
- 3) parents who lose an adult child to AIDS during a year

In addition, separate estimates are made for:

- a) all parents
- b) parents age 60 and older.

The estimates utilize the following information:

- 1) Projected annual numbers of adults dying from AIDS, adults living with HIV/AIDS at year end, and the number of adults on ART at year end for the period from 2001-2010. This information comes from recent projections for Thailand (Analysis and Advocacy Project and Thai Working Group on HIV/AIDS Projections 2008). The projections do not provide this information by age.
- 2) The age distribution of adults dying of AIDS during the years 2001-2010. This information comes from the Projections for HIV/AIDS in Thailand 2000-2020 published by the Thai Working Group on HIV/AIDS Projection in 2001 (TWG 2001).
- 3) The mean number of living parents (all ages and age 60+) in the general population by age based on the 1994 Survey of Elderly in Thailand (SET) conducted by the National Statistics Office (the only nationally representative survey that provides such information).

In order to make the estimates the age distribution of adults who are living with HIV/AIDS, who are on ART, and who die of AIDS is needed. Since the new projections do not provide this informa-

tion, the age distributions of adults dying of AIDS and of those on ART are assumed to be the same as that for those projected to die of AIDS during the years 2001-2010 produced in TWG projections issued in 2001 . The age distribution of persons on ART is assumed to be similar to that of persons who were projected to die of AIDS because for the period covered most persons who start ART are likely to do so after progressing to AIDS. This would be about a year or so of before when they might have died had they not taken ART. At the same time people who continue to live on ART become older than they would have been had they not taken ART and died. For the period covered, these two factors are likely to more or less cancel each other out. In contrast, the age distribution of adults who are living with HIV/AIDS will be lower than those who die of AIDS. For the present exercise their age distribution is assumed to be on average five years younger than those who die of AIDS in the 2001 projections.

The mean number of living parents (of all ages and ages 60 and over) of adults who are living with HIV/AIDS, who are on ART, and who die of AIDS, is assumed to be the same as for persons of the same age in the general public as calculated from the 1994 SET. Based on the assumed age distributions (as described in the preceding paragraph), an age-weighted average of the mean number of living parents is calculated for adults living with HIV/AIDS, adults on ART and adults who died of AIDS. Estimates of the number of living parents of adults in each of the three categories are then calculated in two steps.

First, the numbers of adults in each of the three categories as provided by the new preliminary projections is multiplied by the respective age-weighted mean number of living parents. Second the results are adjusted for the proportion of adults in each category who are siblings and thus have the same parents and would therefore be double counted. To adjust for this, 2 per cent of adults dying of AIDS in a particular year, 4 per cent of adults on ART in a particular year, and 8 per cent of adults who are living with HIV/AIDS are assumed to be siblings. These adjustment factors are based on the following reasoning. Only a very small proportion of adults dying of AIDS in a particular year are likely to be siblings. A somewhat higher proportion of adults on ART at the end of any year are likely to be siblings because persons on ART continue to live for some years (thus increasing the chance that siblings could be on ART at overlapping times). Also the rapid spread of ART during the period being covered (i.e. 2001-2010) means that the average duration of being on ART during this period will be relatively short. The proportion of siblings will be highest among

adults living with HIV/AIDS since persons can survive with HIV/AIDS for an average of about 7-10 years and longer if treated with ART thus providing longer periods for siblings to be living with HIV/AIDS simultaneously. While these assumptions are largely arbitrary they seem in line with simulations published earlier indicating that multiple losses constitute 12-33 per cent of lifetime losses of adult children to AIDS by parent (Ken Wachter et al. 2002). Results of these estimates are provided in the table.

Table. Annual estimates of the number of parents potentially affected by HIV/AIDS in Thailand, 2001-2010

| Year | Parents with adult child living with HIV/AIDS at year end | | Parents with adult child on ART at year end | | Parents losing adult child to AIDS during year | |
|------|---|-------------|---|-------------|--|-------------|
| | all parents | parents 60+ | all parents | parents 60+ | all parents | parents 60+ |
| 2001 | 855 841 | 355 825 | 4 607 | 2 712 | 65 836 | 38 764 |
| 2002 | 822 316 | 341 887 | 14 913 | 8 781 | 57 521 | 33 868 |
| 2003 | 797 037 | 331 377 | 27 991 | 16 481 | 49 724 | 29 277 |
| 2004 | 786 725 | 327 090 | 65 808 | 38 747 | 30 022 | 17 677 |
| 2005 | 782 794 | 325 455 | 121 113 | 71 310 | 24 681 | 14 532 |
| 2006 | 708 023 | 376 120 | 135 420 | 93 250 | 24 094 | 16 591 |
| 2007 | 694 964 | 369 183 | 161 230 | 111 022 | 28 766 | 19 808 |
| 2008 | 677 092 | 359 688 | 184 050 | 126 736 | 31 205 | 21 488 |
| 2009 | 656 887 | 348 955 | 204 049 | 140 507 | 32 068 | 22 082 |
| 2010 | 634 881 | 337 265 | 220 312 | 151 706 | 32 581 | 22 435 |

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Almost three decades into the worldwide HIV/AIDS epidemic, a key dimension of the lives of persons living with HIV/AIDS (PLHA) in the Asia-Pacific region is still often overlooked, namely the impact on their families, especially older parents. How have older-age parents been affected by the epidemic? What role can they and other family members play to help societies cope with the epidemic? Now that access to antiretroviral therapy (ART) has increased, how has its availability changed the impact of HIV/AIDS on the lives of the parents and family members?

The well-being of PLHA cannot be viewed in isolation from their wider social environment. This study takes us through the journey of PLHA, their parents and families in Thailand. It provides insight into the issues they face and puts forward key recommendations that have a bearing on the Asia-Pacific region and beyond.